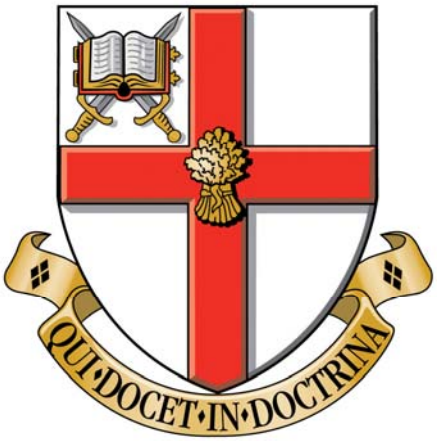

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Title: Experiences and evaluation of weight control approaches among polio survivors

Date: October 2012

Originally published as: University of Chester MSc dissertation

University of Chester

Experiences and Evaluation of Weight Control Approaches among Polio Survivors

Dissertation submitted in accordance with the requirements of University of Chester for the Degree of Master of Science

October 2012

Frances Quinn

Word count: 15680

Acknowledgements

Thanks go to the University of Chester and the staff of the Clinical Sciences Department and Centre for Exercise and Nutrition Science who have contributed to making the MSc course so informative and enjoyable.

Thanks to the administration staff for answering some very silly questions and help at deadline times.

Special thanks go to Mike Morris and particularly to Stephen Fallows for his support and advice on this dissertation.

I have to apologise to my cat who has been sorely neglected and now retires automatically to the sofa when the computer is switched on.

Abstract

Purpose: this study explored the experiences of polio survivors with weight control to determine if it was a particular issue for this group and to assess what interventions are used, how limited mobility has been taken into account, and what factors contribute to success or difficulty.

Method: A questionnaire was advertised on the British Polio website and in its member magazine. A thematic analysis was used on the responses to open questions.

Results: 141 replies were obtained. The age polio contraction age and physical disability level matched that published from the UK epidemics. These were divided into lifetime weight managers, active weight managers and weight gainers for analysis. Eleven themes emerged on feeling around weight and successes and difficulties on weight control. These showed that weight control is an issue for polio survivors and is strongly linked to mobility. Successful methods used were similar to general population studies. Issues emerged on the dietary strictness observed, the beliefs on ability to exercise and the support available from professionals.

Conclusions: Polio survivors are concerned about weight control, most because of its effect on mobility. Some are at risk of nutritional inadequacy. The beliefs about exercise need to explored in more depth due to the impact on health. The use of BMI risk thresholds may not be relevant for this group

Keywords: mobility, disability, under-nutrition, BMI

Declaration

This work is original and has not been previously submitted in support of a Degree, qualification or other course.

Signed.....

Date.....

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Chapter 1. Introduction

The aim of this study is to investigate the experiences of people with low mobility with weight control and weight control interventions, both self-directed and medically advised. The population group of polio survivors has been chosen as an example of a group with long-term, almost whole-of-life physical disabilities.

1.1 The Public Health issue

1.1.1 Obesity and Health in the UK

The 2010 UK statistics show that the proportion of the population either obese or overweight is 62.8%, with the percentage for men higher than that for women (Figure 1). These values have increased between 1993 and 2001 with some indication that the trend after 2001 is beginning to flatten (National Health Service, 2011).

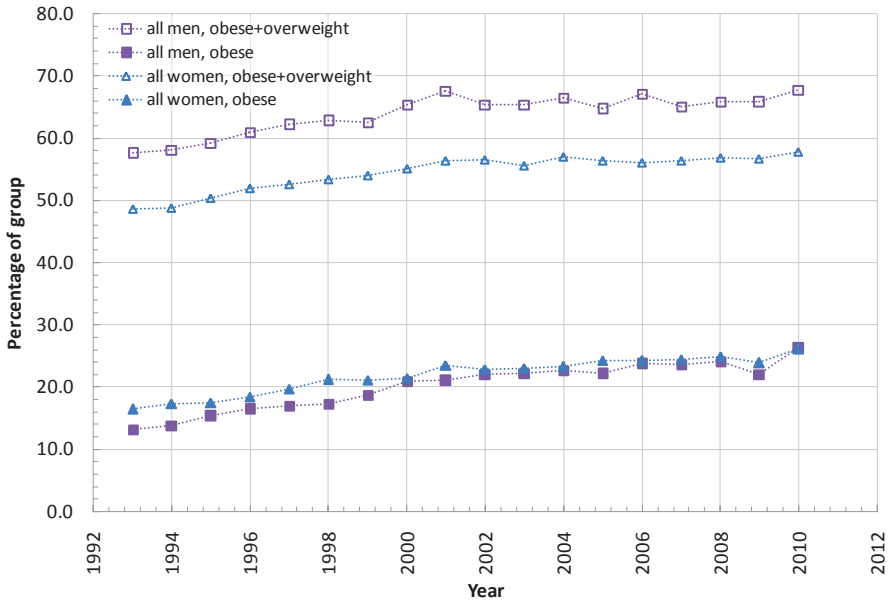

Figure 1. Percentage of men and women obese and overweight between 1993 and 2010 (data extracted from National Health Service, 2010b)

Table 1 gives the increased risk of developing certain associated diseases for the obese (body mass index (BMI) > 30 $kg.m^{-2}$); the data behind this tabulated summary date from 1983 to 1998 but are consistent with recent research. For example, the strong association of obesity with risk of diabetes is supported by Bilous, Donnelly, and Williams (2010), the association with cancer by World Cancer Research Fund (2007) and the association with mortality from heart disease, stroke, cancer and mortality by the Prospective Studies Collaboration (2009). It should be noted that these statistics are generally observational and show an association between obesity and disease - this does not prove a causal link as confounding variables or reverse causality could also produce an association. The use of Mendelian randomization (Davey Smith & Ebrahim, 2003) has recently provided evidence to support a causal link between ischaemic heart disease and BMI, though this link could be through factors such as hypertension or type II diabetes (T2D). The odds ratio calculated for ischemic heart disease was 1.26 (95% CI 1.19–1.34) for every 4 kg/m^2 increase in BMI (Minelli et al., 2012).

Table 1. Relative risk of developing associated diseases for the obese, data copied from National Audit Office (2001).

Disease	Relative risk - women	Relative risk - men
Type 2 Diabetes *	12.7	5.2
Hypertension	4.2	2.6
Myocardial Infarction	3.2	1.5
Cancer of the Colon	2.7	3
Angina	1.8	1.8
Gall Bladder Diseases	1.8	1.8
Ovarian Cancer	1.7	
Osteoarthritis	1.4	1.9
Stroke	1.3	1.3
* Non-insulin dependent diabetes mellitus (NIDDM)		
Note: The BMI range for the obese and non-obese groups used to estimate relative risk varies between studies, which limits the comparability of these data.		

The level of risk increases with overweight and obesity (see Table 2); 57% of adults are at increased risk of certain diseases based on their weight and waistline measurements (National Health Service, 2012).

Table 2. Categories of increased risk as a function of BMI and waist circumference, (National Health Service, 2010a) .

BMI classification	Waist circumference		
	Low	High	Very high
Normal (18≤BMI<25 kg/m2)	No increased risk	No increased risk	Increased risk
Overweight (25≤BMI<30 kg/m2)	No increased risk	Increased risk	High risk
Obesity I (30≤BMI<35 kg/m2)	Increased risk	High risk	Very high risk
Obesity II (35≤BMI<40 kg/m^2)	Very high risk	Very high risk	Very high risk
Obesity III (40≤BMI kg/m2)	Very high risk	Very high risk	Very high risk
For men, waist circumference of less than 94 cm is low, 94–102 cm is high and more than102 cm is very high.			
For women, waist circumference of less than 80 cm is low, 80–88 cm is high and more than 88 cm is very high.			

1.1.2 Policies and recommendations to maintain a healthy weight

The high and rising levels of obesity and overweight described above, coupled with the strong association with a range of chronic diseases have driven government and medical strategies for combating the trends (Foresight, 2007; National Audit Office, 2012; Royal College of Physicians, 2004). While these describe the problem as having a complex range of causes with 'economic, environmental, social and cultural factors', all tactics aim to redress the energy balance of individuals. The national guidelines in the UK and elsewhere (National Institute for Health and Clinical Excellence, 2006, 2008b; U.S. Department of Agriculture and U.S. Department of Health and Human Services, 2010) consist of a two-pronged approach of reducing energy in (diet) and increasing energy out (activity).

This raises several questions. How is weight best managed when the ability to be physically active is limited? What advice and support is most effective? Is the special case optimally dealt with in the health professions? Is there a special problem with weight if activity is restricted?

1.2 Poliomyelitis in the UK

Epidemiological studies show that people with physical disabilities have an increased likelihood of overweight or obesity than those without such problems; odds ratios in one review vary from 1.2 to 2.96 depending on type and severity of the disability (Liou, Pi-Sunyer, & Laferrere, 2005).

The present study focuses on the sub-group of disabled people in the UK who contracted poliomyelitis (polio). Approximately 120,000 people in the UK are estimated to have continuing and increasing effects from an original infection with polio during the epidemics in the 1940's and 50's (Department of Health, 2005).

This group is taken as a case study for the effect of limited mobility on weight gain and on the efficacy of interventions for such subjects. The outcome of looking at this subgroup is likely to be of benefit to those with other long-term conditions which have a similar effect on muscle function and mobility such as multiple sclerosis and spinal cord injury; ~50,000 and 36,000 respectively in the UK, (Department of Health, 2005).

1.2.1 What is polio?

Poliomyelitis is an infectious disease contracted by invasion of the gut by one of three serotypes of polio virus (Mueller, Wimmer, & Cello, 2005; Salisbury, Ramsay, & Noakes, 2006). It can multiply in the gut for 1-3 weeks following which it can be controlled by the immune system. It is estimated that 95% of infections are asymptomatic or cause a flu-like illness. If not contained by the immune system, it can enter the bloodstream.

In less than 1% of infections it enters the central nervous system attacking motor neurons, denervating muscles and causing paralysis (Nathanson & Kew, 2010) and even death if the respiratory system is attacked (Mueller et al., 2005). During the acute phase, patients were confined to bed, usually in fever hospitals.

An analysis of the degree of severity for notified cases in England and Wales for 1947 and 1949 showed the majority of cases to be moderate or mild while in

hospital (Bradley & Gale, 1948 - author's names as given in the reference; Bradley & Gales, 1951).

This phase is followed by a period of recovery lasting between a few months and two years where some degree of motor function is restored. The mechanism is attributed to re-innervation of muscles fibres by axon sprouts allowing large numbers of muscle fibres to be innervated by small numbers of surviving neurons (Grimby, Stalberg, Sandberg, & Sunnerhagen, 1998). Patients were usually treated in orthopaedic wards or hospitals as much of the treatment related to reducing skeletal deformity due to extensive muscle loss.

1.2.2 Degree and nature of disablement

The resulting relatively stable disability had a wide range of severity and could affect any combination of limbs or other areas and in some analyses varied with age of infected subjects.

93% of the total amount of recovery of motor function takes place in the first 12 months, with almost all recovery complete by two years (Sharrard, 1955). The degree of residual disability is dependent on the degree and extent of paralysis of the muscles. Modifying the Medical Research Council (MRC) scale for muscle strength (see historical review in Compston, 2010), Sharrard (1955) assessed the degree of recovery from paralysis (see Table 3). One third of totally paralysed muscles remained at scale 0; of the rest, the recovery was mostly at the level of two scale points after 24 months from onset.

Table 3. Scales for assessing muscle strength

MRC Scale		Scale used in paper	
0	No contraction.	0	No contraction.
1	Flicker or trace of contraction.	1	Flicker or trace of contraction.
2	Active movement with gravity eliminated.	2	Active movement with gravity eliminated.
3	Active movement against gravity.	3	Active movement against gravity.
4	Active movement against -gravity and some resistance.	4	Active movement against -gravity and some resistance.
		5	Active movement against gravity and considerable resistance. (additional step proposed in paper)
5	Normal power	6	Normal power (within the limits of manual. assessment).

Reported cases have been primarily in infants between one and fours years old (Bradley & Gale, 1948; Donaldson, Dane, Briggs, & Nelson, 1960), indicating that many polio survivors are going to be still of working age and requiring support for 20 years (given typical life expectancy).

1.2.3 Late effects of polio and post-polio syndrome

In the 1980's, the term 'post-polio syndrome' (PPS) was used to describe new symptoms in survivors with previously stable disability; these include new muscle weakness, fatigue, pain and new muscle atrophy (Bouza, Munoz, & Amate, 2005; Farbu et al., 2006; Latham et al., 2007). The generally accepted cause of PPS is the 'wearing out' of surviving neurons that had re-innervated large muscle fibre areas (Trojan & Cashman, 1997, 2005) though other aetiologies are also being studied (Boyer et al., 2010; Lupu et al., 2008).

The capacity for exercise in people with the late effects of polio (PPS) has been assessed by comparing physical performance to reference values (Willen & Sunnerhagen, 1999). This showed for example peak workload for men with PPS on a bicycle ergometer to be 61% ± 29% of predicted values with a high correlation to the muscle strength of their stronger leg. A relevant characteristic of the performance data was the wide variation of capabilities of the people with PPS,

with 75% of the test group outside the 95% confidence interval of the reference values; this supports a need for activity guidelines and thus calorie targets to be matched to widely varying abilities.

The key characteristics of polio survivors are summarised in Table 4

Table 4. Key characteristics of polio survivors

Wide range of degree of muscle loss, ranging from no visible effects to total paralysis
Varying post-polio symptoms of pain, fatigue
Probably vulnerable muscle systems
Most likely to be between 55 and 70
Number affected as large as other neurological conditions
Psychological and physiological adaptation mostly done as a child - largely ignore condition

1.2.4 Polio survivor surveys

There have been several surveys of experiences and needs of polio survivors in the UK. Zarb and Oliver (1993) conducted a study of aging with a disability with inputs and interviews from people with diabetes (30%), history of polio (20%) multiple sclerosis (11%) and other disabling conditions (also as a special report for the British Polio fellowship (Zarb, 1992)). The purpose was to raise awareness of the practical issues of older people disabled in childhood or early adulthood. While this report focuses on qualitative experiences and support needs, problems with weight gain/loss (sic) was reported by 33% of polio survivors compared to 21% of all subjects. The two reported quotes referring to weight were on weight gain issues; 33% relates to 20 subjects identifying this as a problem. The most common problems reported in the survey were decreasing mobility (57%), arthritis (36%), increased pain (36%) and energy level changes (36%); all of these are affected strongly by weight. While these are not high quality data with statistical rigour, it

indicates that the polio survivors are recording weight as an issue, but it is not receiving research priority.

The highest priority in the 1980's and 90's for the polio community was to gain medical recognition and support for post-polio syndrome, this is evidenced by three further UK studies (Arshad, 1998; Field, 1995; Pentland, Hellawell, Benjamin, & Prasad, 1999)and one Irish survey (McFarlane, 2004). These were aimed at assessing the prevalence and nature of PPS and requirements for support; the campaign has continued recently (Polio Survivors Network, 2011). Weight does not feature as an issue despite the repeated concerns on decreasing mobility. All of these surveys reported that medical professionals had a poor awareness of the issues of living with the after effects of polio.

1.3 Research questions

In summary, a high proportion of the UK population is overweight or obese. This is associated with increased risk of certain diseases. Polio survivors report issues such as mobility and pain that are affected by excess weight, but due to limited mobility may have difficulty following national guidelines for a healthy lifestyle.

The study aimed to address the following research questions:

> What are the experiences of polio survivors with weight control? Is it a particular issue?
>
> What interventions are used, how has limited mobility been taken into account, and what factors contribute to success or difficulty?

Chapter 2. Literature Review

2.1 Search strategy

The literature was searched for published studies on weight management in polio survivors, both in terms of efficacy and participants perspective. The search terms and numbers found are given in Table 5 showing an almost complete absence of published papers on weight management and polio. Returned searches are included in Appendix 1. Due to the very limited number found, the search was widened to include other groups with limited mobility. In addition, searches were made in the scientific and public health fora for effectiveness of weight management interventions.

Table 5. Number of papers found for some different search terms using Pubmed

	no population	Polio	Disabled	Experiences	Post-Polio
no parameter		22974			438
weight	1,014,274				
obesity	166,292	21	373		
weight maintenance	1,230				
weight loss	54,766				
weight management		0	6		
weight maintenance or weight loss	55,249	13	99	257	

Other papers were found from citation lists and examining reference lists. Polio survivor web sites were helpful in listing polio relevant research (for example http://www.poliosurvivorsnetwork.org.uk/). New article alerts from the National Obesity Observatory (NOO) and relevant journals were a good source for studies on the general population.

Figure 2. Number of papers found per year using the search term 'polio'. The table is copied from the Pubmed search window, http://www.ncbi.nlm.nih.gov/pubmed.

The priorities of polio research are evidenced in the number and topics of papers published per year. The peak publishing rate was in the 1950's in response to the polio epidemics in the UK and elsewhere and focus on epidemiology, physiology, treatment and vaccine development. The second peak in the late 1990's is in response to the emergence of post-polio syndrome (PPS) and the goal of world-wide polio eradication. The PPS research is focused on identifying the existence and nature of the syndrome and determining a treatment strategy.

Little emphasis appears in the research literature on the more general health and well-being issues of polio survivors.

2.2 Weight and Polio

2.2.1 Guidelines for care of polio survivors

Since the 1990's, nearly all advances in relation to primary care of polio survivors have been driven by the need for diagnosis and treatment of post-polio syndrome. The European Federation of Neurological Societies (EFNS) produces evidence based guidelines with classification schemes for therapy and diagnosis (Brainin et al., 2004). The EFNS task force on post-polio syndrome has produced the highest quality review found and has developed recommendations for diagnosis and management (Farbu et al., 2006; Farbu et al., 2011). This EFNS guideline is based on a review of the literature and a questionnaire on care available in the UK, the Netherlands, Norway, Poland and Sweden completed by the relevant task force

members. The task force concluded that the scientific evidence for the benefit of reducing weight was limited, though adding their consensus view that people with '*weak muscles benefit from losing weight'*.

The Cochrane Collaboration systematic review on treatment for PPS was published too late to be included in the EFNS guideline update (Koopman et al., 2011). While this included ten interventions, it excluded on the basis of the review criteria studies on weight control as well as ones on aerobic exercise, resistance exercise and lifestyle management. None of the listed 11 excluded studies were directly studying weight management. Most tellingly, they conclude *'Due to insufficient good quality data and lack of randomised studies it is impossible to draw definite conclusions on the effectiveness of interventions for PPS'.* This supports the finding of this study that the topic of weight management for polio survivors has not yet been fully addressed.

These evidence reviews have informed recently produced guidelines for primary care in the UK (by the National Health Service, NHS), in Scotland (by the Scottish Medicines and Scientific Advisory Committee, SMASAC) and in Ireland (Latham et al., 2007; NHS Map of Medicine, 2011; SMASAC Working Group, 2011). The benefit of weight reduction is recommended in all of these to improve mobility and reduce pain and fatigue. In examining the references providing the evidence base for these guidelines, a very few studies are cited, none of which are looking at weight management directly, and several give other guidelines as evidence. For example, the NHS Map of Medicine (2011) advises weight control to reduce pain and fatigue and cites the Irish guidelines in support (Latham et al., 2007). These in turn support their recommendation for weight reduction by citing a cross-sectional study of 126

PPS patients by Vasiliadis, Collet, Shapiro, Venturini, and Trojan (2002) which found BMI to be a predictor of bodily pain.

In all of these there are no references to studies examining how a population group with low mobility such as polio survivors might best approach losing weight. The only published study found from Korea (Liou, Wang, et al., 2005) demonstrated only that in a group of 31, polio survivors did lose weight following a 3 month programme consisting of exercise (three hours per week at between 11 and 13 rating of perceived exertion), diet education (target between 1200 and 1600 kcal/day) and behaviour change. This study noted that the weight loss of between 1.2 and 3 kg at 3 months was low compared to non-disabled groups and that body fat measurements showed a trend for this to be due to muscle rather than fat loss. This was a small scale longitudinal study with no control group, but it did highlight some of the possible issues with weight loss for polio survivors: inability to meet exercise guidelines for weight loss, some subjects were unable to cook themselves and relied on caregivers, possibility of loss of lean mass.

In summary, no guidelines exist on care of polio survivors, only on those with PPS. There are consistent recommendations to maintain a healthy weight in order to minimize PPS symptoms, but these are founded on beliefs similar to those expressed by the EFNS task force and a few studies where weight has been a side issue. No advice is given on how best to manage weight and only one small study has been conducted.

2.2.2 Polio survivors and health: Risk factors

A Danish longitudinal study of over 5000 polio survivors followed for 20 years on average showed that they had an increased risk of pulmonary, gastrointestinal,

heart and locomotive diseases compared to a matched cohort (Nielsen, Rostgaard, Askgaard, Skinhøj, & Aaby, 2004). The observed incidence rate ratio (IRR) of 1.2 to 1.3 was not large overall, but was higher for certain morbidities and age of contraction of polio; for example those who required ventilation in the acute phase (respiratory polio) with a contraction age of less than four had an IRR for heart disease of 1.70 (95% confidence interval (CI)= 0.65-3.98). No results were presented on weight of the subjects. A smaller less rigorous US study (Gawne, Wells, & Wilson, 2003) on 88 patients selected consecutively from a post-polio clinic attendance list showed a higher level of cardiac risk factors (dyslipidemia in 61.3% of women; 57.8% of men) compared to the national average (dyslipidemia in 49% of women; 53% of men). Tersteeg, Stolwijk, Beelen, and Nollet (2011, September) at the most recent European conference on PPS links these and other data on comorbidities in polio survivors to two lifestyle factors: daily physical activity and excess body weight. Several other papers at the conference showed that exercise could be undertaken by polio survivors but stressed the need for specially targeted and supervised programmes (Nollet, 2011). Some evidence for the success of improving physical activity comes from a pilot study of outcomes from the only known multi-disciplinary rehabilitation programme for PPS in the UK (Davidson et al., 2009).

There is evidence that polio survivors have a higher risk of diseases, some of which are linked to overweight in general population studies. There is also evidence that exercise can be undertaken by polio survivors under supervision.

2.2.3 Polio survivors and body composition

The impact of lean body mass loss referred to by Liou, Wang, et al. (2005) is likely to affect categories of health risk determined by BMI. It has been stated for some time

that recommended BMI targets may not be appropriate for polio survivors (Dean, 1991), but it is only recently that detailed studies have been carried out.

K.-H. Chang et al. (2011) in Taiwan measured the body composition of 17 middle-aged ambulant polio survivors and compared the results to matched controls (matched for age, sex, weight and height). Body composition was measured by dual-energy x-ray absorptiometry (DXA) in the head, thorax, abdomen, arms and legs. The results showed that those who had poliomyelitis had a percentage total body fat between 10 and 14% higher than matched controls, with the largest difference in the thorax (7.7 ± 2.1 kg compared to 3.9 ± 1.0 kg; $p<0.05$). Of the polio survivors, all but one was obese using percentage body fat definitions (>28% men, >40% women), but the BMIs were all in the range 20-30 $kg.m^{-2}$ - not obese by Caucasian-based BMI categories; half were in the Asia-Pacific obese range of > $25kg.m^{-2}$ (C. J. Chang et al., 2003).

In a Brazilian study on 16 polio survivors and 18 sedentary controls using DXA (Bargieri et al., 2008), no significant difference in percentage body fat (%BF) was found, but the total fat free mass was lower for the polio group (53.2 ± 8.7 kg compared to 63.2 ± 6.0 kg; $p<0.05$). These groups were not matched for weight; the polio survivor group was significantly lower at a mean of 70.5 ± 12.7 kg compared to 81.6 ± 8.4 kg for the control group. Their results for %BF are lower than the results from K.-H. Chang et al. (2011) and though no significant difference was found between the polio group and controls, the trend was consistent in the polio group having a higher average %BF for a lower BMI than the controls. This study also found the basal metabolic rate (BMR) to be lower in the polio group by a mean difference of 214 $kcals.day^{-1}$ (95% CI = 14.4 – 441 $kcals.day^{-1}$). When adjusted for body mass, lean body mass, fat-free mass and body surface area the between group

difference was not significant. The measured BMR of the polio group was significantly lower than that derived from predictive equations. They conclude that this could be due to loss of muscle mass and needs to be taken into account when determining nutritional requirements.

A much larger US study looked at BMI and waist circumference differences in groups with various physical disabilities including 443 polio survivors with PPS (Alschuler et al., 2012). The data was gathered by questionnaire and self-reported. This showed that BMI was lower in nearly all the disabled groups studied when compared to the general population. The PPS group was lower for 50 -80 yr old men by about 1 $kg.m^{-2}$, and for women by about 1.5 $kg.m^{-2}$ ($p<0.05$). However, there was no difference in waist circumference when compared to the general population. They conclude that waist circumference may be a better indicator of health risk.

Taken together, these studies show that polio survivors may present with a BMI category that is not a good indicator of adiposity and health risk. All three recommend that target values for weight and nutrition (total calories and nutrient content) should take into account the physiology of the polio survivor.

2.3 Weight and limited mobility

Most of the literature on physical disability and obesity concerns overweight as a causal factor for disabling conditions; relatively few papers address the issues that physically disabled people have in controlling weight.

As mentioned in the introduction, epidemiological studies show that people with physical disabilities have an increased likelihood of overweight or obesity than those without such problems. The review by Liou, Pi-Sunyer, et al. (2005) included

studies that showed increases of fat mass and decreases of fat-free mass in people with a range of physical disabilities including spinal cord injury, multiple sclerosis and muscular dystrophy – suggesting that common clinical measures (eg BMI) may underestimate adiposity, hence overestimating target weights. The mechanisms for weight gain in a disabled population are varied – some mooted examples are low activity, low resting energy expenditure, difficulty cooking/shopping, medication, fear or embarrassment when exercising (Nosek et al., 2008). These are similar to the difficulties mentioned in the polio weight management study by Liou, Wang, et al. (2005).

Again the literature search found little research on weight management. A review of management of obesity for people with spinal cord injury (SCI) only found one published small scale weight loss study (Rajan, McNeely, Warms, & Goldstein, 2008). This review identifies the need for special guidelines and proposed clinical recommendations for weighing SCI people and identifying relevant exercise options.

One interesting point arises from a large scale study of obesity using data from US national health surveys in 1994 and 1995 (Weil et al., 2002). This showed again the increased likelihood of obesity for disabled people. In particular those with severe lower extremity mobility difficulty had the highest odds ratio of obesity (OR=2.5, 95% CI 2.3-2.7) while also having the lowest odds ratio for attempting weight loss or receiving exercise counselling (OR= 0.7, 95% CI 0.5-0.9 and OR=0.5, 95% CI=0.4-0.7, $p<0.05$ respectively).

Even in the wider physically disabled population, the same issues arise as with polio survivors: little specific well conducted research or guidelines on weight management exist, and the use of general BMI and nutritional targets are likely to be inappropriate.

2.4 General Population

2.4.1 Guidance

The National institute for Health and Clinical Guidance (NICE) has produced clinical (National Institute for Health and Clinical Excellence, 2006) and public guidance on the management of overweight and obesity (National Institute for Health and Clinical Excellence, 2008b). These are based on energy balance strategies and consist in eating a healthy low-fat, high fibre diet with five portions of fruit or vegetables daily, watching portion sizes and avoiding too many calories from alcohol. In addition, its latest review of evidence (National Institute for Health and Clinical Excellence, 2011) added that lifestyle and behaviour interventions have been found to be successful, some evidence for group behavioural interventions being superior to individual, that diet was more effective than exercise, both diet and exercise together was most effective, that diet composition did not appear to be a significant factor and that very low calorie diets were not effective in the long term. In terms of physical disability, the guidance only notes that this could be a barrier to lifestyle change and that there was little UK based evidence relevant to this group.

The target BMI of between 18.5 $kg.m^{-2}$ and 25 $kg.m^{-2}$ recommended by NICE to reduce health risk may not apply to older age groups. A recent systematic review indicated that the lowest mortality occurred for the overweight BMI category in people over 65 years old and that body fat distribution should be taken into account when developing guidelines for the elderly (S. H. Chang, Beason, Hunleth, & Colditz, 2012).

Energy balance requires matching energy intake to expenditure. The published UK recommended energy intake values (Scientific Advisory Committee on Nutrition, 2011) included information on less mobile, physically disabled people in recommending use of data for a lower physical activity level (PAL) and recognized that this may also overestimate energy intake requirements. **The review notes the difficulty in estimating total energy expenditure (TEE) for people with abnormal body composition such as loss of muscle mass.** It discussed the hypothesis that energy balance may be harder to achieve at low physical activity levels, but viewed that supporting evidence is weak.

The UK guidelines on physical activity recommend at least 150 minutes per week of moderate intensity activity along with muscle strengthening activity twice a week while also avoiding extended sedentary periods (Department of Health, 2011). The report did not review evidence on physical activity and disabled people and acknowledged that there is much less research on the topic. It concluded that '*the guidelines can be applied to disabled adults, emphasising that they need to be adjusted for each individual, based on that person's exercise capacity and any special health or risk issues'*.

These three key UK documents are based on methodical reviews of the literature both in the UK and worldwide and conducted by national and international experts along with web-based consultation processes. As such, they provide a reliable review of the available evidence. Of relevance for this study, they support the conclusion of the previous section that **little research has been done on weight management for physically disabled people. They also show that there is recognition at policy level that this area needs to be tackled.**

2.4.2 Weight management delivery

There is a wide range of products and services available for weight management; self-determined, PCT or local authority commissioned or commercially delivered. Self-determined is considered here to be activity that is self-selected and managed and includes for example self-determined diet (perhaps using books or the internet for input), exercise such as sport, walking, swimming or other hobbies and self-monitoring.

A very diverse range of programmes are available via PCTs and local authorities including healthy eating and physical activity promotion, behavioural therapy, cooking skills and exercise referrals. These use both group and one-to-one contacts. In some areas, services have been audited to provide information on the number, type and scope of interventions by geographical area (see for example, Head (2011); Roberts and Marvin (2010)) .Most programmes are unique and locally developed and of less than 20 week duration. The audits either do not mention provision for physically disabled persons or only a very few programmes include them as a target group. A table is included in Appendix 2.

Commercially delivered programmes are widely advertised and available nationwide; for example Weight Watchers, Lighter Life, Jenny Craig, Slimming World. Many are accessed via general practitioner (GP) referral for a defined period.

2.4.3 Effectiveness of weight management programmes

Despite the introduction of a Service Evaluation Framework (SEF) by the National Obesity Observatory (Roberts, Cavill, & Rutter, 2009), it is difficult to find standardized evaluations of effectiveness of primary care interventions as use of the framework is in its early days and perhaps for the reasons cited by Head (2011)

(commercially sensitive data, data protection, desire to publish before inclusion in an audit).

Some evaluation data has been published for commercial programmes, though the authors often have competing interests due to employment or funding by the commercial organization under study (Ahern, Olson, Aston, & Jebb, 2011; Finley et al., 2007; Stubbs et al., 2012).

Available evaluations (for example, Morrison et al., 2011; Nanchahal et al., 2012) of UK weight management programmes show that they are quite successful in the short term of the intervention (between eight weeks and one year, typically 12 weeks). All programmes showed significant weight loss at the end of the intervention (frequently reported results were weight loss >5% of starting body weight for 30% of those completing). Completion rates varied from 10% to over 70% of starters. Most make no mention of effectiveness for physically disabled people, and in one study, they were specifically excluded (Jebb et al., 2011). A table is included in Appendix 3.

The Health Technology Assessment (HTA) programme of the UK National Institute for Health Research (NIHR) has performed a systematic review of the effectiveness of long-term weight management schemes for adults (Loveman et al., 2011). The inclusion criteria were at least 18 months follow-up, randomized controlled trials, well-described multi-component approach as recommended by NICE (National Institute for Health and Clinical Excellence, 2006) and for a BMI > 25 $kg.m^{-2}$. The main conclusions were that these interventions did result in weight loss. However, though starting from over 3000 identified references giving 159 meriting retrieval, only 12 met the inclusion criteria for the assessment of clinical effectiveness, none of which were from the UK. Weight changes were found to be small, mean weight

losses at the first follow-up at 12 to 24 months from the studies range from 0.39 to 9.7 kg but with large standard deviations (for example a typical study gave a percentage BMI reduction of 7.8% with s.d.=7.9%). Studies with longer follow-up periods of over 30 months showed that weight regain was common with a net weight change of -0.1 to 1.4 kg.

This review found several issues with assessment of clinical effectiveness. Firstly, the very small number of studies of high enough quality to be included - the most common reason for exclusion of retrieved papers was insufficient length of follow-up followed by insufficient detail in the intervention. The included studies and the interventions were different, covering a range of different diets, exercise and behaviour regimes making overall interpretation difficult, about half were published in the 1990's and so may be of limited relevance. No UK studies were included showing a need for research in this area.

While this is a high quality systematic review, it usefulness in assessing the effectiveness of interventions for weight management in the UK for people with long-term mobility problems is very limited. The review shows that weight management interventions can work, but rate of weight loss is small with best mean weight loss being around 0.8kg/month, very different from the quoted target in guidelines of 0.5-1 kg/week. The high standard deviation showed high variability within the study populations. Weight loss did not seem to be sustained after completion of all intervention phases. Of prime relevance to this report, no account was taken of interventions for people with mobility limitations.

There is evidence that weight management programmes are available and work in the short term; little evidence exists of inclusion of disabled people.

2.4.4 People's perspective

Qualitative studies can explore people's weight management experiences over the life course thus extending the timescale from a few years to many decades. This timescale more closely matches the length of time relevant to long term disabling conditions.

One such study looked at slimmers' beliefs about the causes of weight gain (Sawkill, Sparkes, & Brown, 2012). Themes that emerged from the analysis included the importance of habit driven by time constraints, childhood learned behaviour and using food to help with difficult situations.

A thematic analysis of qualitative interviews with 20 Scottish volunteers identified successful strategies for long-term weight maintenance (Chambers & Swanson, 2012). These included a staged approach, monitoring, defined goal and trigger point for taking corrective action and acting quickly with small adjustments. The people who gain weight over the lifespan tended to have emotional reactions to weight, poorly defined goals, taking action was mood dependent and they disliked or didn't use exercise. Weight loss was viewed as separate from normal life rather than built into a lifestyle.

Another small scale UK qualitative study interviewed ten women who had lost 10% body weight, maintaining the loss for at least one year (Hindle & Carpenter, 2011). The participants had used a range of weight loss approaches such as commercial, general practice and self-determined. Most reported that viewing weight loss as a long-term change was necessary for successfully maintaining weight loss. Other factors involved developing a more relaxed, less diet-oriented mindset, avoiding banning any foods, self-monitoring, overcoming lapses quickly and listening to their bodies. Enjoyable physical activity helped with weight loss as did group or

professional support. The lack of positive reinforcement in the maintenance phase due to no longer seeing weight change was overcome by creating goals appropriate for maintenance such as role-modelling for others or helping others in health-based activity.

The research by de Souza and Ciclitira (2005) on male perspectives showed that men also considered support important. The researchers discussed the different image pressures on men, for example to look muscular not just slim. The change in women's self-image upon losing weight was explored by Epiphaniou and Ogden (2010). The transition reported was from a weight-centered self to a liberated self and that this process of reinvention could facilitate long-term behaviour change of importance to weight maintenance.

In a US cross-sectional study of 155 people on a waiting list for weight loss research doing it on one's own was the most often tried approach with 30% of those who recorded a favourite method selecting it - the primary reason given was the sense of control. Other close favourite methods were commercial (22.8%) and research programmes (19.6%) with programme and peer support as the main reason (Burke, Steenkiste, Music, & Styn, 2008). Note that this study excluded people with 'physical limitations precluding ability to exercise'.

Ruelaz et al. (2007) have found significant differences in the perspectives of 'patients' and providers in terms of barriers to weight management with patients more likely to believe they should manage their own weight and providers more likely than patients to believe that primary care providers should be more involved helping patients with weight management.

In a US study of preferred weight loss methods, the National health and Nutrition Examination Survey (NHANES) was used to access a nationally representative sample of adults with BMI > 30 $kg.m^{-2}$ (Nicklas, Huskey, Davis, & Wee, 2012). This found that 40% of those who tried to lose weight in the previous year lost more than 5% body weight. However, only 9.9% joined a weight loss programme even though this was the most strongly associated with success (along with medically prescribed diet drugs). Most commonly, 65% reported eating less food and 55% reported exercising.

The National Weight Control Registry (NWCR) in the US follows over 4000 successful weight maintainers, defined as people who have 'intentionally lost >10% of their body weight and kept if off for at least one year'. Their published data show that 44.6% did this on their own with 54% accessing assistance from weight loss programmes or professionals (Wing & Phelan, 2005). Only 10% reported using diet alone as opposed to 89% using diet and exercise (approximately 1381-1800 kcal/day and 1h/d moderate intensity activity). Successful strategies for weight loss involved low-calorie low-fat diet, physical activity, regular breakfast, monitoring of weight and a consistent eating pattern. Triggering events leading to success included medical reasons (23%), all-time high weight (21.3%) and seeing images of themselves (12.7%). A follow-up study looking at weight regain risks showed that 59% maintained weight loss, 6% lose more weight while only 35% gained more than 2.3 kg. The length of time people maintained their weight strongly predicted the one year risk of regaining; >5yrs gave an odds ratio of 0.29 compared to those who had <2yrs of successful maintenance. A recent cluster analysis performed within this registry identified sub-groups who used different weight control behaviours. Of interest for this study is the identification of a cluster of 10% of particpants who did

not rely on physical activity to maintain weight, on average reporting levels of only 727 kcal per week, about a third of the levels within the three other identified clusters (Ogden et al., 2012).

The behaviours associated in the above studies with long-term weight maintenance are listed in Table 6.

Table 6. Behaviours associated with long-term weight management

Successful behaviours	Staged approach Monitoring Goals Triggers for action, prompt action Taking a longer view More relaxed approach Avoid banning foods Listening to own body Enjoyable exercise Positive reinforcement in maintenance New appropriate goals and self image for maintaining weight
difficulties	Habits Childhood learned behaviour Emotional eating Poor goals Action depends on mood Not liking/doing exercise Weight control separate from normal life Male image – looking muscular
Methods used	Many self-determine Some need professional/group support Some are successful with diet only Low calorie/low fat diets Some use physical activity Eating breakfast Consistent eating patterns
Motivations	Medical Triggered by reaching high weight Triggered by seeing image of self
Other points	Can take over 5 years to embed new weight control strategies Physical activity not essential

2.5 Literature review summary

The literature search has shown there is little research on polio survivors and effective weight management, perhaps because of the focus on PPS in recent decades. Polio survivors have been shown to be at higher risk of certain diseases, but BMI risk categories may not be appropriate due to body composition differences. Nutritional guidelines may also not be relevant due to low levels of

activity and low lean body mass. These conclusions also apply to other physically disabled populations.

A wide variety of weight management programmes exist and are successful in promoting weight loss over the short term, but long-term maintenance requires additional skills and support. Few weight management programmes address physically disabled people's needs.

Chapter 3. Method

3.1 Approach

Despite the previous surveys of UK based polio survivors discussed in the literature review, there is almost no information on weight and weight management issues for this population group. A qualitative bottom-up method was chosen as the most appropriate method for open exploration of people's experiences without limitation by a pre-existing framework (Denzin & Lincoln, 2011; Pitney & Parker, 2009). Much qualitative research is based on interviews (Pitney & Parker, 2009); the selection of a questionnaire method for this study allowed many more hard to reach people to participate within the time frame for the study and prioritised the breadth of exploration.

3.1.1 Researcher's background

Horsburgh (2003) discussed the role of reflexivity in relation to the credibility of qualitative research – this *'refers to active acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation.'*

The researcher's '*actions and decisions*' are affected from also being a polio survivor, having contracted the virus 54 years ago at the age of one, resulting in significant muscle loss and difficulty walking. From about the age of 40, weight control has been a recurrent problem leading to the present interest in successfully dealing with the combination of weight and mobility limitations. The researcher's background was made clear in the Participant Information Sheet and would have been obvious to any groups talked to in person.

This background also made access to the British Polio membership easier, with appreciation expressed by groups and in questionnaire responses of the likelihood of the meaning behind issues being better understood.

3.2 Participants

British Polio is a national charity supporting polio survivors in the UK. With over 6000 members, a nationally distributed members magazine and web based information, it has been used for earlier surveys (Field, 1995; Zarb, 1992) and was selected as an ideal way to reach a wide range of polio survivors.

British Polio members also hold local group meetings, usually monthly. There are 49 groups spread over England, Scotland and Wales and attendance at meetings is in the range 5-20, though local membership can be between 30 and over 50 – difficulty travelling to meetings which for some members can be an hour's travel away is a barrier to attendance. Use of a questionnaire advertised nationwide and available by post or internet was chosen to reach as broad an audience as possible.

Data from earlier surveys showed that the majority of polio survivors in the UK are aged between 50 and 80 having contracted polio below the age of 10 in the epidemics of the 1940's and 50's. The membership of British Polio covers only about 5-10% of the estimated UK polio population and so may not be fully representative.

Of relevance for a weight management study, the physical ability of survivors was expected to range from wheelchair users to the fully ambulant. A target of > 100 responses was set to allow significant differences between subgroups to emerge.

Inclusion criteria were history of contracting polio and age over 30 as the study was aimed at identifying successful weight management approaches over the life course. Exclusion criteria are near total immobility as this was likely to require

medical supervision of nutrition and also medical conditions affecting health which are unrelated to polio or overweight, for example chronic obstructive pulmonary disease (COPD) or type I diabetes.

3.3 Ethical approval

Ethical approval for the study was obtained from the Faculty of Applied Sciences Research Ethics Committee at the University of Chester (the approval letter is attached in Appendix 4). Informed consent was implicit in completing and returning the survey questionnaire; the Participant Information Sheet was attached at the front of paper copies of the survey and as the first page of the online version.

3.4 Procedure

3.4.1 Development of the questionnaire

The aim of the survey was to collect qualitative data in the form of descriptive perspectives on weight. Due to the age range of the study population, the questionnaire was kept to 20 straightforward questions so that it could be filled in without assistance and take no more than 30 minutes.

Three open questions explored experiences and feelings on changing weight, difficulties and successes in weight management. A fourth open question allowed for any further comments.

Some quantitative questions were included to understand the context of the responses in terms of mobility, weight history, activity and health. Questions 1 and 2 relate to current age and age of contracting polio. Question 3 asked for a description of the level of muscle loss and was based on the commonly affected areas reported by Olin (as cited by Nathanson & Kew, 2010). Some subjectivity was

expected in terms of degree as very few people have a formal record of a clinical assessment for example using the Medical Research Council scale of muscle power (Compston, 2010; Sharrard, 1955). Also, it has recently been accepted that polio can result in neuromuscular damage in a manner that does not show up for many years (Farbu et al., 2011).

Questions 4, 5 and 6 asked for self-reported mobility information and were based on typically used assistive devices and mobility assessment such as used in the Disabled Living Allowance application form (now replaced see

http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG_10018702)

Although many validated physical activity questionnaires exist including those for elderly and disabled people (Loland, 2002; National Obesity Observatory, 2011; Washburn, Zhu, McAuley, Frogley, & Figoni, 2002), these were too long and detailed for the purpose of this study. Question 8 instead drew on commonly used descriptions (Chief Medical Officer, 2004; NHS, 2006).

Questions 9, 10, 11 and 12 asked for biometric and health data for comparison to the latest published trend tables from the Health Survey for England (National Health Service, 2010b).

The online questionnaire was produced using Survey Monkey (SurveyMonkey.com, LLC , Palo Alto, California, USA; Experiences with Weight Control among Polio Survivors, http://www.surveymonkey.com/s/KGXFRKR , last visited 29/8/2012).

The questionnaire is attached in Appendix 5.

3.4.2 Trial

The web-based questionnaire was sent to a small group of six polio survivors known to the researcher as a check before dissemination via the magazine article – three responded with no issues raised and no changes were made as a result.

3.4.3 Dissemination

The survey was advertised by an article in the British Polio Fellowship magazine (see Appendix 6), the Bulletin, and a link on their web page. Both directed people to the online survey and gave contact details to request a hard copy version. Both methods were used to take account of the age range of the target population (50-80yrs) and to reach as wide an audience as possible.

The study was further promoted by distribution of paper copies at three 'local' polio support groups (Manchester, Liverpool and Chester), and by sending paper copies to British Polio regional groups via their local secretaries for distribution (a total of 50 paper copies distributed). Some local secretaries also printed copies from an emailed file.

3.5 Analysis

3.5.1 Thematic analysis

The method of thematic analysis as described by Braun and Clarke (2006) was selected to extract meaningful information from the text responses to the open questions. The process used has also been informed by grounded theory approaches to coding data (Charmaz, 2006).

Braun and Clarke (2006) describe five phases -

Familiarization → initial coding → identification of themes → reviewing themes → defining themes

These phases were incorporated into the procedure as follows.

- Familarisation
    - Both paper based and web based survey responses were collated into an Microsoft Excel 2007 spreadsheet via the Survey Monkey manual entry and data download tools
    - A unique ID was assigned to each to maintain confidentiality of the respondents throughout the analysis
    - Responses were read and scanned as they arrived to check for errors
    - Answers to open questions were collated into tables for each question
- Initial coding
    - These tables were coded line by line (Charmaz, 2006, p. 50) and segments colour coded for each topic (example tables are attached at Appendix 7)
    - First pass at raw codes – production of first list
- Identification of themes; first pass grouping under broad trial themes
- Reviewing; themes were then reviewed, trial thematic maps produced, themes reviewed for 'internal and external homogeneity' (Braun & Clarke, 2006) and for relevance to the research questions – using constant comparison of subthemes with each other and with main themes
- Themes defined and thematic map produced
- Focused coding of the text using these defined themes (Charmaz, 2006, p. 57) - this involved re-analysing the text with reference to extracting quotes relevant to the final themes
- tables of collated extracts for each theme were added to the Excel spreadsheet (example in Appendix 8)

3.6 Quantitative analysis

The emerging themes relating to weight issues and weight management difficulties and successes were the primary outcome of the research. Nevertheless, some quantitative analysis was performed to support the interpretation of the data, for example, looking for significant differences in BMI between sub-groups. For this, PASW Statistics Version 18 software was used, along with Microsoft Office Excel 2007 built-in functions.

Chapter 4. Results

4.1 Respondents characteristics

4.1.1 Overview – response to survey

There were 141 responses to the survey; three from the early trial, 106 online, and 32 paper copies via postal returns. Of these, there was one fully unusable web entry and 27 web entries with no responses to the open questions leaving 113 responses providing the qualitative data. The quantitative data is given in Table 7. The ages of respondents is plotted in Figure 3.

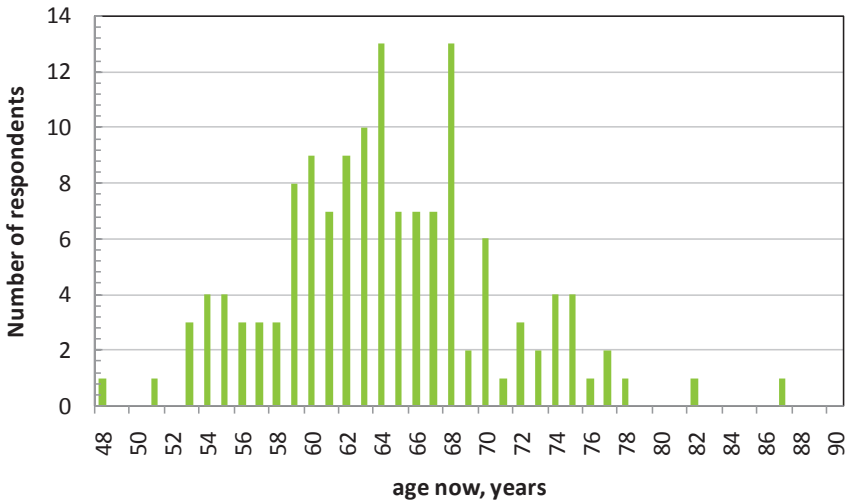

Figure 3. Age distribution of questionnaire respondents

4.1.2 Representativeness of the sample

The respondent's data was examined to assess how representative they were of the estimated polio survivor population in the UK. Figure 4 shows the respondent's year of contraction of polio compared to the Health Protection Agency notification data (Health Protection Agency, 2011). This closely follows the peaks of incidence.

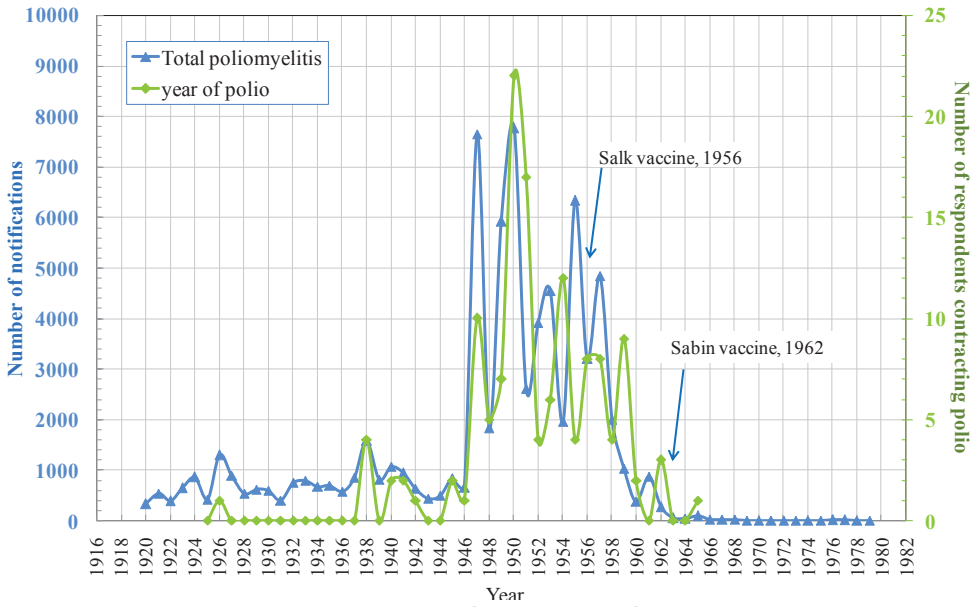

Figure 4. Respondents age of contraction of polio compared to the epidemiological notification data for England and Wales. The offset by about one year for respondents is due to rounding up to complete years in people's memories and the process of binning the data.

The age of contraction of polio is maximum between one and three years, consistent with data for England and Wales from Bradley and Gale (1948).

The areas affected are shown in Figure 5; most commonly affected areas are the legs, consistent with data from Sweden (Olin as cited in Nathanson & Kew, 2010).

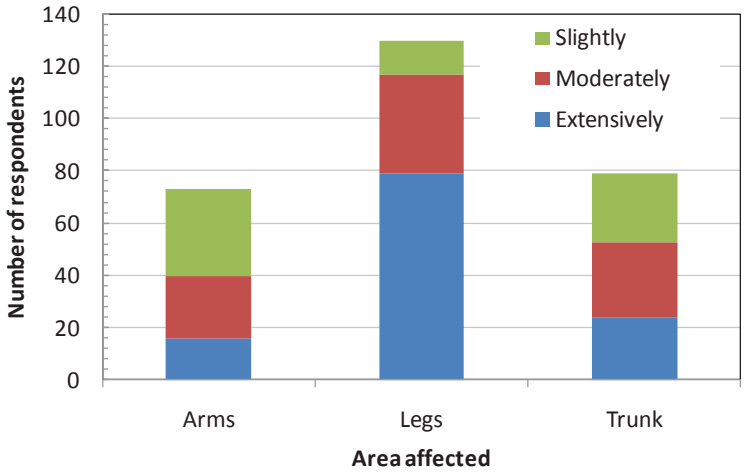

Figure 5. Degree and location of disablement due to polio

In summary, the survey respondents have be taken to be a good representation of survivors of polio epidemics in the UK. More detailed background data is given in Appendix 9.

Table 7. Quantitative data giving the participants characteristics listed by survey question number (left column). Number of respondents for each question is given in the right column

Q	Characteristic						No.
1	age when contracted polio, median (range) years	3 (0-19)					139
2	age, median (range) years	64 (48-87)					140
4	mobility: main method of getting about	motorised wheelchair	self-propelled wheelchair	walkings or rollator	no aids		
	number (%)	22 (16%)	18 (13%)	65 (48%)	30 (22%)		135
5	walking distance	around the house	10-15 mins	15-90 mins	longer		
	number (%)	57 (42%)	46 (34%)	23 (17%)	9 (7%)		135
6	number whose mobility has changed since recovering from polio	112					124
8	Activity level	sedentary	low	medium	high		
	number (%)	48 (38%)	58 (46%)	16 (13%)	3 (2%)		125
9	state of health	poor	fair	good			
	number (%)	46 (37%)	60 (49%)	17 (14%)			123
10	number with one or more potentially weight related co-morbidities	total	BMI<25 kg.m^{-2}	BMI>30 kg.m^{-2}			125
	some co-morbidity	71 (57%)	10 (34%)	30 (75%)			
	high blood pressure	51	6	19			
	high cholesterol	29	5	14			
	type II diabetes	6	0	5			
	other possibly relevant co-morbidities						
	sleep apnoea	3					
	thyroid problems	9					
11	BMI, median (range) kg.m^{-2}	29 (18-55)					107
11	waist/hip ratio, median (range)	0.87 (0.68-1.21)					91
11	current BMI category	underweight	normal (healthy wt.)	overweight	obese (obesity I&II)	morbidly obese (obesity III)	
	number (%)	1 (1%)	28 (26%)	38 (36%)	32 (30%)	8 (7%)	107
11	current waist category	low	high	very high			68
	number (%)	18 (26%)	17 (25%)	33 (49%)			
14	tried to lose weight	constantly	>5 times	2-5 times	once or twice	never	
	number (%)	50 (45%)	6 (5%)	16 (14%)	24 (22%)	15 (14%)	111
15	difficulty losing weight	yes	no				
	number (%)	83 (76%)	27 (24%)				110

4.1.3 Comparison to the general population

Figure 6 shows that the percentage of respondents in different BMI and waist circumference categories is in general agreement with data from the Health Survey for England 2010 (National Health Service, 2010b). Category names used are the ones from the Health Survey for England and are based on NICE thresholds (National Institute for Health and Clinical Excellence, 2006).

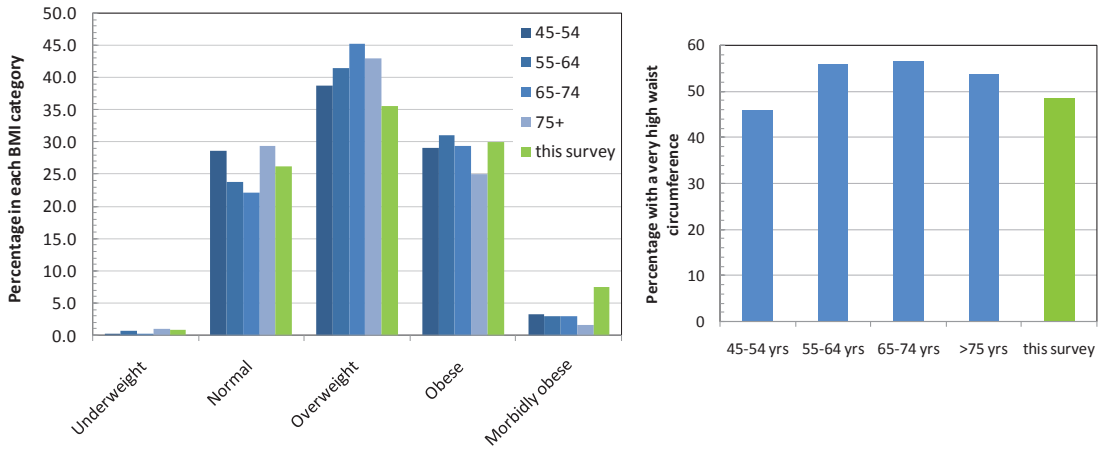

Figure 6. Left: percentages of people in different BMI categories. Right: percentages of people with raised waist circumference (NICE category 'very high'). Data in blue are from the Health Survey for England 2010, data in green are from the current study.

Question 9 asked for a self-assessment of state of health; this is compared to the data from the Health Survey for England 2009 as the most recent published age dependant data (NHS Information Centre, 2010). Figure 7 shows that survey respondent were more likely to report only fair health as opposed to good health compared to the general population (note most of the survey population are between 55 and 74 years old). The reporting of poor health was similar.

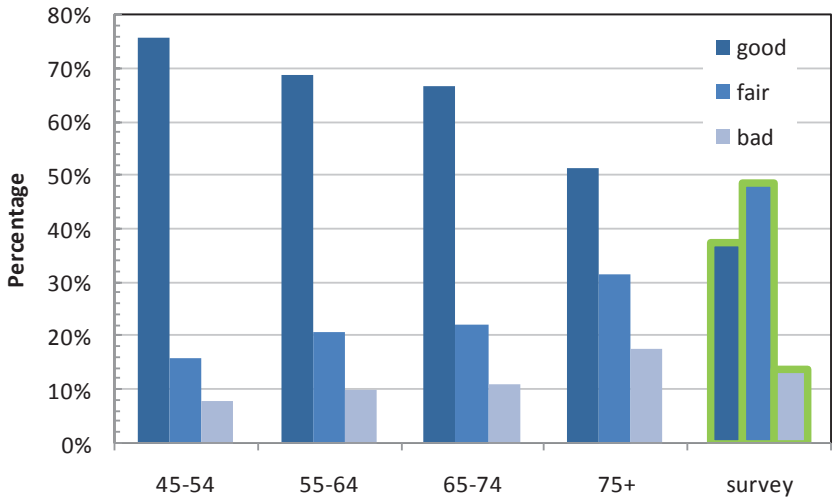

Figure 7. Percentages of people reporting good, fair or poor health for different age groups in the Health Survey for England 2009 compared to this survey

Question 10 asked for reports of high blood pressure, high cholesterol and type II diabetes as these have been shown to be associated with overweight and obesity. First inspection would indicate that all three are lower for the survey group than the

general population, especially that for high cholesterol. However, issues exist with the data and the comparison. The structure of the survey only allowed for one of the three to be selected, though further text could be added in a text box. It is possible this hindered people from entering data. 53 of the 125 respondents who answered this question added text data – as 48 respondents reported 'no other conditions', this indicate that 101 responses are complete. The data in Table 8 include data entered in the text box. They also show that incidence of co-morbidity is higher for higher BMI. In making the comparison, the survey asks for self-reported data whereas the Health Survey for England takes blood sample from over 200 people for each age group and measures cholesterol levels. In addition, the threshold used is 5 mmol.l^{-1}. It is feasible that some survey respondents either have not had a measurement done or that levels above this have not been considered to be 'high' in a doctor/patient consultation (as NICE do not set a specific intervention threshold, 5 mmol.l^{-1} is used as an 'audit' level (National Institute for Health and Clinical Excellence, 2008a)). This data is presented in Table 8 in spite of its limitations; further investigation is required.

Table 8. Percentages reporting co-morbidities

age range	45-54	55-64	65-74	75+	survey 48-87
	%	%	%	%	%
high blood pressure[1]	31	48	64	79	41
high cholesterol[2]					23
men	76	70	53	39	
women	76	83	75	66	
type II diabetes[3]	5	10	14	14	5

1. 1 high blood pressure data is from Health Survey for England 2010
2. 2 high cholesterol data refers to measured blood cholesterol levels over 5 mmol.l^{-1} from the Health Survey for England 2008 (British Heart Foundation, 2010)
3. 3 type II diabetes data refer to doctor diagnosed diabetes of both types and are from the Health Survey for England 2010 – it is estimated that 90% of people with diabetes have type II (Diabetes UK, 2012)

4.1.4 Weight History Groups

Previous studies on weight management use the technique of dividing subjects into groups depending on their weight change history. For this study, groups are defined

along similar lines to those used by Chambers and Swanson (2012). The definitions used here are

- Lifetime weight managers (LWM): respondents whose lightest weight, heaviest weight and current weight are in the same BMI category – their history shows lifetime control
- Active weight managers (AWM): Respondents whose current weight is significantly lower than their highest weight (by around one BMI category) – their history shows weight gain but are actively controlling their weight now
- Weight gainers (WG): Respondents whose current weight is equal to their highest weight and is one or more BMI categories above their lightest weight – their history shows steady gain

Two other categories were used: lifetime obese (LOB) for one respondent with a BMI in the obesity III category throughout adult life, and healthy weight gainer (HWG) for two respondents who increased from being underweight to a healthy weight. Numbers by group and current BMI category are shown in Table 9.

Most respondents are overweight or obese and not successfully managing their weight. A significant number are successfully managing their weight with 25 at a healthy weight.

Table 9. Numbers of respondents in each weight history group

BMI category by weight management group (106 responses)					
	successful weight managers		unsuccessful weight managers		
BMI category now	LWM	AWM	WG	LOB	HWG
underweight	1	0	0	0	0
healthy weight	16	9	0	0	2
overweight	2	9	27	0	0
obesity I&II	0	4	28	0	0
obesity III	0	0	7	1	0
total in group	19	22	62	1	2

4.1.5 Weight Management

Figure 8 shows the number of respondents against the weight management methods tried. Of the 106 people who provided information nearly 90% had used a self-chosen diet, often many times. Nearly 50% had used self-directed exercise, with fewer choosing prescribed diet or exercise. Medication and surgery were relatively rarely used.

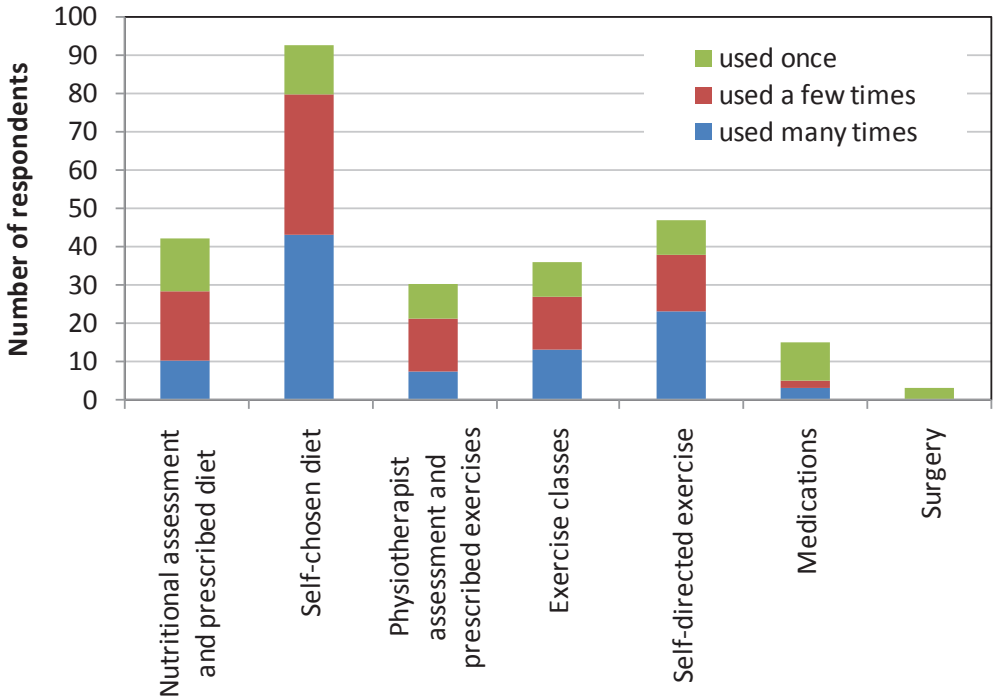

Figure 8. Number of respondent who have used the different methods of weight management

Question 18 asked for views on what methods worked; the data is shown in Table 10. Also shown is the method currently viewed as working now – this was derived from reviewing all the text from each respondent and was not clear in all cases (hence reduced total). While a self-chosen diet was used by many, fewer felt this was working currently. Weight management classes also did not seem to be helpful long term. Intake control was used to describe people who more strongly reported the methods of controlling what they ate rather than the diet itself, for example

using portion control and responding to over-indulgence. Very few reported no problem with weight; in reviewing the text from these three they were emphatic in using exercise and activity so were assigned as currently using self-directed exercise. In summary, many methods worked in the shorter term, but fewer in the long term where emphasis appeared to shift towards lifestyle methods. Attitude was assigned as one method used as this respondent while developing a healthy lifestyle, provided more explanation of attitude changes.

Table 10. Successful methods used by respondents in the past, compared to methods working currently

	Main method that works	
Method	**ever worked**	**works now**
self-chosen diet	31	10
self-chosen diet with exercise	8	9
WM class	9	2
self-directed exercise	8	7
professional (diet)	3	1
professional (exercise)	1	1
monitoring	1	
meal replacement	1	
healthy lifestyle		1
intake control		5
attitude		1
underweight issue		3
no problem with weight	3	0
nothing	39	48
summary		
something worked	62	37
no problem with weight	3	0
nothing	39	48
underweight issue		3
total responses	**104**	**88**

4.2 Thematic analysis

The line by line coding yielded over 700 coded segments (an example coded sheet is shown in Appendix 7). 17 trial themes were refined to 11; these were aligned with the most relevant research topic and are shown in Figure 9. The research questions are examined under three topics: 'feelings' to collate themes on issues relating to weight, 'difficulties' and 'successes' to collate themes interventions. Three themes align equally with two research topics; for example, the theme of support is relevant for both successes and difficulties.

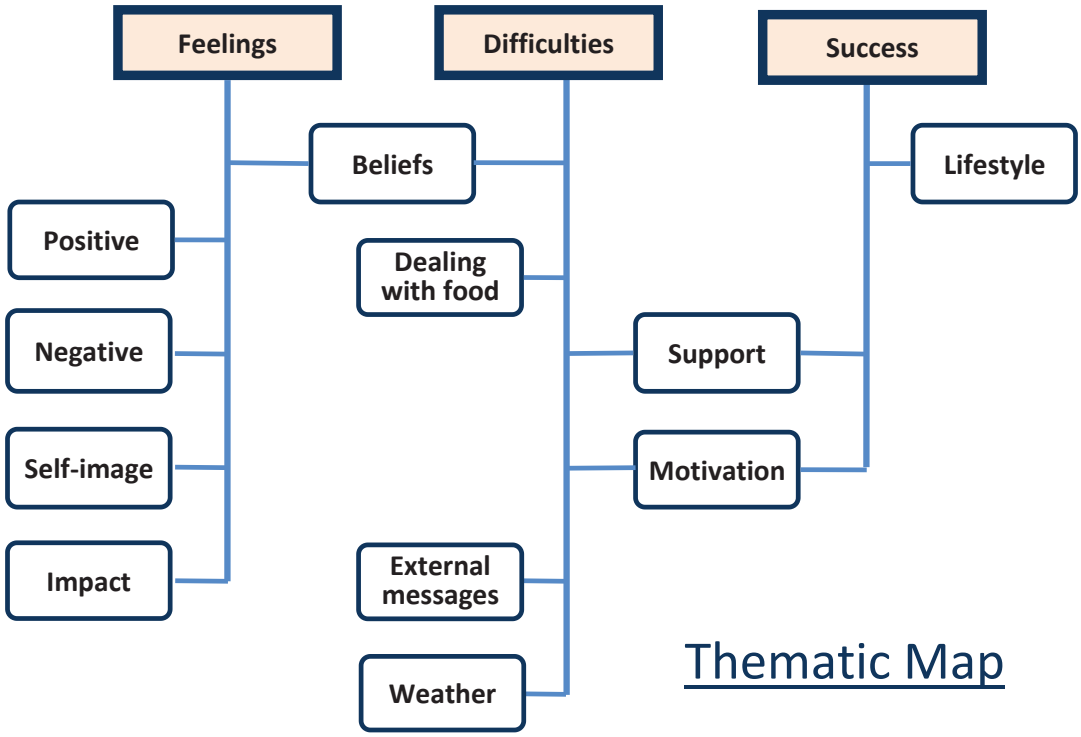

Figure 9. Map of the themes that emerged from replies to the open questions (clear boxes), these have been related to the research topics of feelings, difficulties and successes (shown in coloured boxes)

4.3 Feelings

4.3.1 Positive/Negative

The positive and negative themes under the 'feeling' topic are simply defined as the main feeling expressed in response to Question 13 – 'How do you feel about your

weight?'. For about two thirds of respondents this could be clearly attributed and most emotions expressed were negative. A greater proportion of successful weight managers (LWM and AWM) expressed positive emotions than negative ones while for weight gainers, the vast majority reported negative feelings. The quotes are presented in Box 1 to contrast differences and similarities between the LWM/AWM groups and the WG groups.

A striking difference was in the greater variety of words used to describe negative emotion – this is graphically illustrated in word clouds derived from the two themes Figure 10. The negative words show a high level of distress in relation to weight; many of the positive words also express feelings of something that needs to be 'battle'-d or controlled.

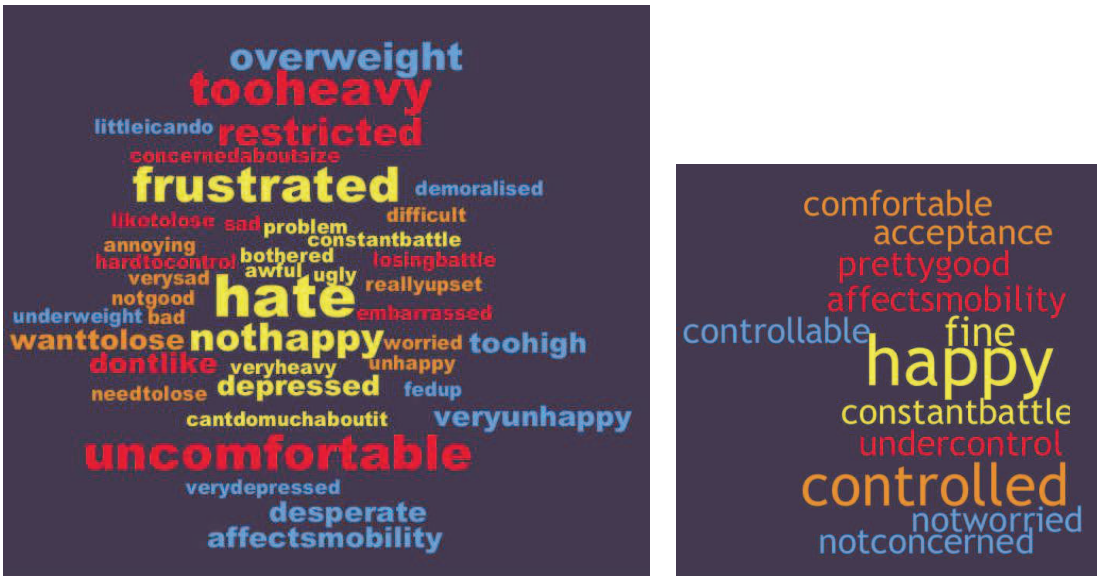

Figure 10. Word clouds of negative words (left) and positive words (right) that respondents used to describe feelings related to weight

Box 1. Positive and negative quotes

	Successful (LWM, AWM)	Unsuccessful (WG)
Positive	*happy. I am concerned, not that I am overweight now, but that I do not want to become overweight (ID 128, LWM)*	*Reasonably happy. It is totally stable and I cannot reduce more however hard I try. (ID69, WG)*
	I'm happy with it and I try to maintain it as I can tell the adverse effect it has when standing or walking if I put on just a couple of pounds (ID111, LWM)	*I have accepted the fact that I hover around the 14.5 stone region. I would like to be thinner but I don't worry about weight issues - except when buying clothes!!!! But that's more of a woman thing. (ID33, WG)*
	Quite happy with my weight and I take care not to eat too much. (ID64, LWM)	*would like to be slimmer but am happy with who i am and how i look so not a big issue with me (ID114, WG)*
	Now I feel OK about it. It's about the middle of normal on the BFI. Easier to walk around and climb stairs. But still have to be careful as easy to put on again. Have already put on 7 lbs in last few months. (ID102, AWM)	*Maybe a couple of Kg overweight I have put on a lot of muscle due to my high swimming activity (ID57, WG)*
	I lost a lot of weight 15 years ago (deliberately) and felt a lot better physically mentally and emotionally. ..... I am starting to put a bit back on which I feel quite upset about. On the other hand I feel quite confident I can stop the gain and lose the few pounds by being a bit more aware of the changes I need to make to allow for my lower activity levels. .... (ID7, AWM)	
negative	*I bothers me, because breathing is harder and i feel uncomfortable. (ID40, LWM)*	*I AM DESPERATE TO LOSE WEIGHT PRBLEMS WITH BREATHING AND MOBILITY PARTICULARLY LIFTING MYSELF FROM SEATED POSITION (ID5, WG)*
	I have been aware of polio and weight all my life. The more weight the harder it is to walk, especially with a calliper which you swing to walk. It puts pressure on you spine and back. Now I have to leg supports, it is even harder. I don't worry about weight from the point of view of looks. .....Since being back in the UK, I find it harder to control eating and weight control, plus the lack of exercise. (ID63, LWM)	*I hate being so overweight as none of my clothes fit properly and don't feel attractive. I also get very frustrated when I read articles in women's magazines which tell me that if I want to lose weight I have to do more physical activity then give suggestions such as walking the stairs instead of using the lift none of which I can do. (ID141, WG)*
	Hate it! It's restrictive as it slows me down; I can't see my feet and I feel miserable as, short of starvation, it won't budge. (ID17, AWM)	*frustrated ugly fat hopeless However much I try to control my weight I seem to fail. I know I should exercise but this seems to become more and more difficult..(ID115, WG)*
	It has been a problem since a long stay in hospital in my teens. The food was poor, and our parents "topped up" at visiting time. ..... I hate my weight. .....You can avoid other substances if addicted, but you have to eat. ..... Having been nagged about my weight since being a teenager, and knowing I should keep it down, I just seem to go about feeling guilty about eating, and having an addiction to food. (ID84, AWM)	*Very depressed. Managed to keep my weight under control until I got in my forties. Then had an illness which I now believe was the start of post polio syndrome as I was then unable to keep active (because caused to much pain in joints). I know I must lose weight to help my mobility but because of depression its a vicious circle. I comfort eat! (ID74, WG)*
	I am trying to lose weight and keep weight off my legs I feel it is a losing battle as I cannot get enough exercise. I go swimming twice a week but it doesn't seem to help. If you can come up with something please let me know (ID78, AWM)	*Frustrated - it is such a struggle to maintain a healthy weight especially as I cannot do a lot of physical exercise. I am embarrassed about the shape of my body due to my weight.... (ID15, WG)*

4.3.2 Belief

This theme arises from beliefs in the reasons for weight management problems. The inability to exercise was the highly dominant reason given.

'can't exercise'

What ever I eat seems to put weight on. I am very aware of eating healthy and nutritious food - am very aware of saturated fats, sugar and salt and try all the time to read labels carefully when I go shopping in order to buy the healthiest option I can. I try to eat plenty of fruit and veg, eat food with good fibre content and limit as much as possible saturated fats, sugar and salt. I truly believe that the main cause of my difficulties comes mainly from the fact that I cannot exercise very much. I certainly do not eat great quantities and it is extremely difficult to achieve weight loss without the added benefit of exercise. (ID15)

I am trying to lose weight and keep weight off my legs I feel it is a losing battle as I cannot get enough exercise. I go swimming twice a week but it doesn't seem to help. If you can come up with something please let me know (ID78)

I feel very uncomfortable because it seems to affect my walking & without being able to walk very far I feel I am not getting enough excercise which is keeping my weight high. (ID8)

One respondent defined exercise '*unable to exercise to increase heart rate. Cant walk far or run (ID80)'.*

While many attributed weight problems solely to inability to exercise, some did link this with intake and energy balance.

Energy balance

Frustrated!! No matter how little I eat I do not seem to be able to loose any weight in-fact as time goes by I just seem to put on more and more weight. I do realize that the problem is lack of mobility and I should eat less and less but hey...you only have one life, and it's short! (ID26)

unable to exercise and enjoy food (ID24)

lack of exercise due to my condition and eating too much of the wrong foods (ID92)

However, the limit for calorie intake in order to lose weight may not be well understood given the answer from respondent ID62, a 60 year old man who had led a physically active, sporting life

intake

could do with losing 2-3 stone but can't exercise and am only eating 2000-2500 cals/day not much I can do about it (ID62)

Changing ability did not only change activity level, but also emotional state.

As I become less mobile simple tasks are an effort. It has made me feel depressed as in the last year I gained a stone for no particular reason apart from having to give up aerobic exercise once a week.(ID36)

Other beliefs that emerged much less often were that weight increase was due to age, family traits or will power.

Age

Weight slowly increased with age, which is something my able bodied friends have also experienced, the difference is I find it difficult to improve my level of aerobic fitness without causing pain.(ID98)

I feel that I need to try to be as active as possible within the confines of my wheelchair, as when walking this was very hard work (like a good workout) to walk around. Now of course, i don't get this kind of exercise. However, I also feel my weight gain is part of the ageing process (ID67)

Family trait

I am very unhappy about being overweight. I was never overweight when I was a child but it is a family trait on my mother's side although my brother isn't overweight (ID91)

lack of will power is the only explanation (ID130)

4.3.3 Impact

'Impact' collates polio survivor's comments on the impact on them due to overweight. By far the most common response was that being overweight had a significant impact on their mobility, with some referring to increased pain and reduced quality of life.

mobility

I am constantly aware of being overweight as I feel this contributes to limiting my mobility and increases the pain in my arms as I have to walk with a stick, haul myself up steps and out of chairs etc. I felt much better about myself when my weight was reduced by swiming, but without exercise my weight balances ar 12st (ID61)

Very depressed. Managed to keep my weight under control until I got in my forties. Then had an illness which I now believe was the start of post polio syndrome as I was then unable to keep active (because caused to much pain in joints). I know I must lose weight to help my mobility but because of depression its a vicious circle. I comfort eat! (ID74)

would like to keep weight under control as the heavier I get it is more of a strain on my weakening muscles, and then I become more immobile (ID140)

4.3.4 Self-image

A few respondents referred to self-image and weight. For some, this was related to how being overweight made them feel unattractive.

I hate being so overweight as none of my clothes fit properly and don't feel attractive. (ID141)

I feel very embarassed & unhappy about my weight even though I realise I could be more in control over my diet I obviously comfort eat so only have myself to blame (ID130)

Horrid. Hate it! Makes me feel unattractive. (ID82)

Two more poignant comments related how even if they lost weight, they still would not have a positive physical self-image

I have a huge ribcage and my upper body developed to compensate for my weak legs. I know I would look ridiculous below 10 stone - therefore I am being realistic in my weight loss goals. (ID10)

I think food became a comfort for me. Women seem to overeat for various reasons. With me, I did it mainly because living with a deformed body is hard. (Polio left me with a curved spine and restricted my growth)... .....You must be thinking, "Why the hell doesn't she lose the weight?" Certainly being more mobile would have helped but another reason for me is 10stone or 7 stone, I'm still deformed. (ID13)

4.4 Successes/difficulties

4.4.1 Lifestyle

Many people volunteered information on lifestyle choices that helped control weight; twice as many comments came from successful as opposed to unsuccessful weight managers and five times as many from people of healthy weight or overweight as opposed to obese.

Intake control was most commonly quoted and covered low fat, healthy sensible eating, learning to cook, and controlling purchases -

portion control

lack of exercise I guess, because Im in wheelchair and feel worn out most of time, I feel I must eat tea plate size meals to stay stable (ID18, AWM, OW)

low fat, intake control

I am very careful to keep a control on my weight so as not to overburden my legs. I feel that 50 kg is about the right weight for my height and if I go over that I cut down on my food intake until my weight is 50 kg again. I have no more than 28 g of cereal in the morning or one boiled egg, Only one slice of home made bread with a little cheese or spred for lunch and a piece of fruit and I rarely have a pudding in the evening with my main meal. If I do it will be a small portion of Greek youghurt with a small spoonful of jam or honey or stewed fruit. (ID44, LWM, HW)

Some commented on the difficulty of keeping to the level of restriction required –

highly restricted calories

Im still a stone over weight and find I have to live on 900 calories per day to stay stable, if I go over that I gain weight, I feel I just look at food and the

weight goes on, I have been on a diet for 22 years and find it most annoying (ID18, AWM, OW)

Exercise was next in prevalence, with a wide variety including for example gym and equipment based, walking, swimming, gentle yoga/pilates, and seated gardening -

physical activity

Retired due health (mobility) problems age 55 when weight peaked. Knew I was too heavy and consciously increased activity (joined gym/seated gardening) and lifestyle to improve core fitness and reduce weight. Has been stable for 3-4 years and I'm happy with the balance of weight/activity/fitness/lifestyle. Could reduce wine, but I enjoy it and it's not increasing weight! Still attend gym 2x per week, light gardening, diy and outings, eat what I want and social drinking and don't feel I am denying myself - have adjusted and incorporated exercise and diet into lifestyle. (ID83, AWM, OW)

Go to Pilates class every week which I find beneficial although I cannot do all the exercises. I find it keeps me supple & have noticed a difference when not going for a few weeks - example - illness or holiday. I also try to eat as much fruit and veg as I can although I lose my way sometimes (ID131, LWM, HW)

Monitoring featured relatively high, both of weight increase and intake -

daily weighing

I watch what I eat and so weigh myself most days.(ID96, LWM, HW)

monitoring clothes fit

I could feel the weight reduction by how my trousers fitted. (ID113, AWM, HW)

food diary

I keep a daily food diary which I find helps focus on what is good to eat. I do not count calories as I find this too time consuming but by keeping my diary I can glance at it every day and keep an eye on the type of foods I am eating. It is also a quick way of looking at say a weeks worth of food consumed and making sure I am getting plenty of all the good things and very little of the 'naughty' things.(ID15, WG, OW)

A variety of other behaviours were also evident -

taking action

It crept up over 25 years and, once I decided to deal with it it, reduced and I adjusted intake and diet to maintain. No special effort for several years now - temporary increases over holidays, Christmas etc come off without effort when 'normal' lifestyle resumed (ID83, AWM, OW)

Feel that the decisions are mine and I must make them. (ID96, LWM, HW)

adapting

I try to eat healthily all the time and now modify the quantities to accommodate less activity.(ID69, WG, OW)

attitude

strong willpower and nothing else (ID18, AWM, OW)

I am lucky to have a certain amount of self discipline. I have always recognised how important it is to control my weight to avoid putting strain on my legs and also for my husband to be able to lift me when I fall or out of chairs etc. (ID27, LWM, HW)

Similar themes emerged in text from respondents with obese level BMI, though many fewer in number

Keep fit or the gym three tmes a week managed to keep it under reasonable control along with watching eating/drinking. Once my mobility deteriorated the weight started piling on. (ID133, WG, OB3)

Self chosen diet, by controlling calories and smaller portions. My problem is i snack to much, the lifestyle leaves you "nibbling" (ID97, WG, OB2)

Allowing time in my day to to put plans into action (ID77, WG, OB1)

I try to balance food in with efforts to burn calories (ID43, WG, OB2)

4.4.2 Dealing with food

Many of the difficulties cited related to dealing with food, though the problems reported were quite varied. This issue arose more frequently with weight gainers than lifetime weight managers or active weight maintainers. Comfort eating was cited by several, with issues around either feeling unwell or feeling concern about adequate nutrition levels when trying to reduce intake. The importance of eating as a social activity was seen as an unmanageable problem by some, while the temptation to eat was also attributed to inactivity, depression and lack of other distractions.

Comfort eat

After initial enthusiasm, I lose motivation quite quickly. I feel hungry too easily and I know that I "comfort eat". I crave sweet things and seem to need to be crunching something-and I hate chewing gum!(ID35, WG, OB2)

Very depressed. Managed to keep my weight under control until I got in my forties. Then had an illness which I now believe was the start of post polio syndrome as I was then unable to keep active (because caused to much pain in joints). I know I must lose weight to help my mobility but because of depression its a vicious circle. I comfort eat! (ID74, WG, OB2)

nutrition

when I try a new diet or cut down on normal meals, i can lose size, but feel weak and think I need to maintain nutrition to keep my muscles going and my activity level good. So I eat again! (ID87, weight not known)

I try to control my weight as I cannot carry shopping so I cannot afford to give my back and legs the equivalent of extra shopping to carry every day! On the other hand I think it is more important that I am healthy rather than thin, so I will not starve my body of the nutrients it needs. I eat good nourishing food and no junk food.(ID3, LWM, HW)

Social eating

My weight is the bane of my life. It's a constant struggle. I alternate between being on a very restricted regime and being more relaxed about my weight. Having a wide circle of friends, eating out is what I DO and although I know I should have the salad and the fish, I don't always feel like having the salad and the fish. I realise I'll never be 8 stone, or even 10 stone. .....I have to be completely obsessed to lose weight. As my exercise tolerance is drastically reduced it's virtually impossible for me to use up the calories I consume - even on a healthy low fat diet. (ID10, WG, OB3)

Lack of distraction

Not being mobile, I spend more time sitting watching TV playing board games and cards and of course eating! (ID129, weight not known)

4.4.3 Support

The support needed by polio survivors to help in weight control included different sub-themes when accessed successfully compared to instances of it lacking. By far the most prevalent lack was in the knowledge of polio and PPS perceived in

professionals of all types (GPs, physiotherapist, consultants). This was seen by both successful and unsuccessful weight managers. Other difficulties arising from lack of support appeared with much lower prevalence and included transport to group sessions and availability of special scales. Difficulty in accessing pools included provision of a warm enough temperature and feeling safe from being bumped by other pool users.

The support most frequently cited was self-support, followed closely by the benefits of group sessions in terms of enjoyment, exchange of information and motivation. In contrast to topping the list of perceived lack of support, many respondents mentioned positive support from GPs and other professionals. The help of family and friends was quoted by a significant number of both successful and unsuccessful weight managers.

See Box 2 for illustrative quotes.

	Box 2. Support	
	Successful (LWM, AWM)	**Unsuccessful (WG)**
Support used	*Staying in control of my own health is important for me. There is plenty of information around about eating well. I believe in self-help. Staying a reasonable weight is part of my keeping well regime. My husband shops and cooks and is able to support me in this. (ID3, LWM)*	*I have never taken advise on dieting or eating healthy, this something that i have always done for myself (ID50, WG)*
	I was a science teacher for many years so I don't feel that I need to consult any professionals about diet. I have a clear idea of the calorific value of foods and think that the only way to increase weight is to take in more calories than my body needs. (ID44, LWM)	*do research myself, do not speak to professionals (ID80, WG)*
	the ability to talk by myself with a professional. A very caring and helpful G.P. and talking with people with similar difficulties have been a great help. ((ID1, HWG)	*Group work and counselling - being able to discuss with others aspects of the diet and keeping motivated (ID74, WG)*
	Adopting them into daily lifestyle with the support of family and friends (ID83, AWM)	*When my wife was slimming we did it together using Slimming World. (ID139, WG)*
Support lacking	*Apart from two GP's from my local practice and my osteopath (who diagnosed PPS) I have had no help at all from NHS health care professionals (one Neurologist said that because my legs weren't withered and I wasn't a cripple, I couldn't have had polio. All this without checking my notes! ..... I have no faith whatsoever in the NHS and find I am better coping with those around me that I trust.(ID17, AWM)*	*not enough people i.e. doctors and physios know enough about post polio syndrome to be able to help.one physio made me stand and hold onto a chair whilst pushing my foot against a radiator to try and straighten my foot ,all that happened was that i was in severe pain. (ID101, WG)*
	I think what would help me the most at this time would be to have the help of a professional but to join in with people that have similar difficulties as myself. I think also that if I was given advice from a professional person about my diet and about the exercise that I could do, that would certainly help me, but I have tried the physiotherapy route, but the trouble is these people are not yet aware of the problems we suffer as part of the post polio syndrome. All the different GP's and physiotherapists I have spoken too have never heard of it. (ID60, LWM)	*I'm concerned that my GP knew little or nothing about Polio or Post-polio and had to look it up on the computer whilst I was in her office. She initially prescribed Amyltritaline for the nerve pain which made me feel very depressed, odd as they're an anti-depressant. I had to tell her about Gabapentin, which I now take although it only makes a slight difference to the nerve pain. (ID112, WG)*
	Weighing scales are not possible for those who cannot step on unaided, and stand steadily while the weight registers. (My hospital dietician had grab rails at the scales, which helped me to step on.) .....For weight loss groups there is the problem of transport and access, including the availability of parking. Again, these groups are geared towards the lives of able-bodied people. (ID84, AWM)	*I like to swim but the nearest pool is a distance away and i don't drive anymore. I also can't walk far. The surgery are there for me but I don't have continuity . I feel the medical practitioners find me unfocused, which I probably am it all seems such an effort. (ID115, WG)*
	In Australia, I had polio consultants at the Prince of Wales Hospital (POW), Royal North Shore and one in his consulting rooms. I was in the POW when a visiting Professor, a specialist in polio, from Havard, USA was visiting. I met him at a Registrars Meeting. I have never come across this in the UK, nor had an assessment in a hospital in the UK as an adult. (ID63, LWM)	*I found that I was very self-concious about going to a class, being as large as I am now (not by my disability) - they spoke to everyone as a 'whole' not on an individual level. (ID76, WG3)*

4.4.4 Motivation

Examining the reasons that motivate people to take positive action is important input for any weight management initiative. In some responses, reasons for failing to control weight were given and included lack of results, inability to maintain motivation and more commonly depression. It was not possible to distinguish people with clinical depression from low mood.

> *Can't seem to keep it off get very depressed and low so eat again (ID23, AWM)*

> *After initial enthusiasm, I lose motivation quite quickly. I feel hungry too easily and I know that I "comfort eat". (ID35, WG)*

More people gave reasons for taking action. The overwhelming reason was to maintain mobility. A few other reasons arose such as avoiding negative impact on others, keeping healthy and improving self-image.

> *Fear! If you were fit and active as child and then paralised, you have a mental focus on being constantly mobile. (ID43, LWM)*

> *I am very careful to keep a control on my weight so as not to overburden my legs. (ID44, LWM)*

> *I am lucky to have a certain amount of self discipline. I have always recognised how important it is to control my weight to avoid putting strain on my legs and also for my husband to be able to lift me when I fall or out of chairs etc. (ID27, LWM)*

4.4.5 External messages

A few responses make mention of external messages on what exercise is needed for weight management.

I shout at the TV when yet again I am told I must exercise. (ID3, LWM)

everyone seems to think it's my/our fault if i/we don't exercise in a convential way - is to ask my gp for a gym referral, he laughed and wrote it for me on prescription, (ID9)

unable to exercise to increase heart rate. Cant walk far or run. (ID80, WG)

With out moving about the weight will not be lost, and you get told to excrise more, go for a walk and get your heart pumping.(ID105, WG)

I also get very frustrated when I read articles in women's magazineswhich tell me that if I want to lose weight I have to do more physical activity then give suggestions such as walking the stairs instead of using the lift none of which I can do. (ID141,WG)

4.4.6 Weather

The impact of weather occurs a few times in the narrative, all the quotes are given in Box 3.

Box 3. Weather

I have put on some weight recently - I think because increased fatigue has reduced activity, and the 2 recent severe winters left me housebound for weeks and unable to get exercise. (ID84, AWM)

My weight does fluctuate and in winter does go up. I am constantly freezing cold even with central heating and eat more. (ID37, AWM)

Since being back in the UK, I find it harder to control eating and weight control, plus the lack of exercise. I also do not have the medical support and encouragement. In Australia, the climate helps you to not eat so much and what you do eat is a lot more salads. I miss my swimming and exercise. I felt fitter and more in tune both in muscle & lung strength. (ID63, LWM)

Since then my muscles have weakened a lot, my joints ache and I have severe intolerance of cold. (ID3, WG)

Am finding wind and rain cause mobility problems in rt leg (rather than the distance walked) and cold (ID59, LWM)

About 12 years ago I found that I was in a lot of pain all year round. Pain had only been bad in the winter befor. My leg gave way, I lost my balance and fell a lot more, I now fall most days and have had some nasty injureys from falling. (ID105, WG)

4.5 Preliminary statistical analysis

Unlike a structured interview, an exploratory questionnaire cannot probe for information on the same topics from all subjects. However, some statistical analysis could be useful to help shape suggestions for future research. This analysis needs to be treated as only indicative of possible significant differences and correlations.

Numerical scales were assigned to the answers to Question 3 (polio muscles affected), Question 4 (mobility), Question 5 (walking distance), Question 8 (activity) and Question 17 (methods tried). For the polio muscles affected, a weighting multiplier was used of x1 for arms, x2 for trunk and x3 for legs to increase sensitivity to the larger muscles used for walking.

Table 11 shows the correlation between these factors. The most interesting result is that BMI and polio score show no correlation. Only a low correlation exists between BMI and activity, BMI and methods tried, polio and mobility and between mobility

and activity. Walking ability and mobility show a modest correlation as does walking ability and activity. The low correlation between polio score and mobility indicated that assessing polio disablement requires a clinical assessment to remove the effect of respondents subjective assignment of impact level.

Table 11. Correlations between different parameters calculated using PASW Statistics 18

Spearman's rho correlation coefficients	Polio score	Mobility	Walking ability	Activity	Methods tried
BMI	0.00	0.10	**0.25**	0.24	0.25
Polio score		**0.34**	**0.29**	0.19	-0.14
Mobility			**0.67**	**0.34**	-0.12
Walking ability				**0.42**	-0.05
Activity					**0.22**

values in bold, p< 0.01
values in normal type, p<0.05
values in grey type, not signficant

Many replies stated that respondent could not exercise – often in quite terse terms. A Mann Whitney U test performed using PASW Statistics 18 showed a statistically significant difference in the average BMI of the group stating 'can't exercise' compared to the remaining respondents (median BMI = 31 $kg.m^{-2}$, range 21-55 $kg.m^{-2}$, compared to 28 $kg.m^{-2}$, range 18-50 $kg.m^{-2}$, p=0.001). No significant difference in polio score was found between these groups (median = 10, range 3-18 compared to 9.5, range 1-18, p=0.679). (The PASW Statistics 18 data are attached in Appendix 10).

Chapter 5. Discussion

Some aspects of weight management for polio survivors are common to those found for the general population. This section prioritises those areas more unique to the study respondents.

Several additional literature topics were searched for and reported in this section in response to the themes that emerged in the analysis.

5.1 Is weight management an issue for polio survivors?

The high proportion of respondents expressing negative feelings shows that weight management is a stressful issue for many polio survivors. Even for those who expressed positive emotions, this was qualified in many instances by the need for continuous control or acceptance of things as they are.

The dominant sub-theme on the impact of weight was the resulting effect on mobility, followed by self-image and then pain. Reduced mobility or increased pain then heightened the awareness of overweight and general feelings of depression. Having a physical disability results in greater feelings of stress for a degree of overweight that may not affect the non-disabled. The reported negative self-image of feeling unattractive or embarrassed could equally apply to the general population. However, some commented on how even if weight is lost, body shape norms would still not accessible due to musculoskeletal deformities. Epiphaniou and Ogden (2010) studied the change in women's self-image on losing weight. They postulate that a re-invented self can help weight maintenance. This study showed that for some (perhaps many) polio survivors, a positive physical self-image is not available – this may have an impact on motivation for a healthy lifestyle. The

muscular male body image discussed by de Souza and Ciclitira (2005) is also less available for male polio survivors.

When compared to statistics for the general population, the percentage in each BMI and waist circumference category was similar – on the surface, this could indicate that there is no special issue for this population group. However, DXA measurements on body composition for polio survivors show a trend for higher body fat percentage and lower lean mass for an equivalent BMI (K.-H. Chang et al., 2011). Assessment of a healthy body weight by using current BMI classifications (National Institute for Health and Clinical Excellence, 2006) may not be appropriate.

The preliminary statistical analysis showed no correlation between self-reported degree of disablement from polio and BMI and only a very low correlation with activity level. Possible explanations might be that many respondents are working very hard to control weight, perhaps as a result of dealing with a physical disability since youth. The success of such coping mechanisms might depend more on psychological and support factors rather than mobility. To draw confident conclusions in this area would require a clinical assessment of disablement using the MRC muscle strength scale and a validated activity questionnaire such as the Physical Activity Scale for the Elderly (Loland, 2002) along with data on psychological factors.

Respondents reported their health status as somewhat worse than national levels. In contrast, the percentages reporting other conditions related to overweight such as high blood pressure, cholesterol and diabetes are lower than measured national averages. In responding to the question, it appears that some people include their polio related physical disability and some as has been found in other research do not (Nazli, 2012). This has made interpretation of the responses difficult.

Another possible contributor to the disagreement was that some respondents have not been assessed for these risk indicators.

A UK study on body composition and disease risk indicators for this population would be very useful.

5.2 Range of interventions – successes

The trend in the responses for a self-directed approach to weight management (see Figure 8 and Table 10) is consistent with the findings of Burke et al. (2008). The experience expressed by many, that a variety of approaches worked in the past but could not be maintained (see Table 10) is found by many studies that find regain common (see for example Loveman et al. (2011) or Weiss, Galuska, Kettel Khan, Gillespie, and Serdula (2007)).

> *'yes they all worked at the time but became difficult to sustain if you have any kind of social life' (ID10, WG)*

In comparing what people have used in the past to what they report still using, a picture emerges that is almost completely self-managed with a strong emphasis on lifestyle factors such as individually derived eating plans and exercise/activities.

Despite the prevalence of a DIY approach, this does not mean that this works for everyone. Most respondents report that nothing works (Table 10) and a significant fraction also found that the absence of appropriate support is a difficulty (see Box 2).This is discussed later in the section. The support of partners and friends and the availability of information on the web and in books was also considered helpful.

It was more common to use dietary methods than exercise. Several discuss how intake is controlled via portion sizes, not having tempting foods, and by adjusting after overindulging or in response to reduced activity. A few reported skipping

meals and eating very low calorie diets, one estimated consuming 900 kcal per day. Given that polio survivors are talking about a whole-of-life eating plan, it is possible that some diets are nutritionally deficient. The guidance given by NICE recommends a calorie deficit of 600 kcal per day when attempting to lose weight and advise that levels between 1000 and 1600 kcal are 'less likely to be nutritionally complete'. Very low calorie is defined as below 1000 kcal per day and is only advised for 12 weeks. There is an indication in the responses that several people severely restrict calorie intake, apparently without clinical supervision, for many decades. Further study is required to properly assess the incidence rate of extreme calorie restriction and levels of nutritional quality.

The physical activity used varied from home exercise devices like treadmill and rowers, to gardening, walking, swimming, supervised gym session and gentle activities such as pilates.

Respondents used behavioural techniques such as monitoring, taking action and planning.

These lifestyle approaches are commonly associated with successful weight management; most are included in the NICE guidelines (National Institute for Health and Clinical Excellence, 2006). However, the latest review of the guidelines found some evidence that group interventions were more successful than individual (National Institute for Health and Clinical Excellence, 2011)

5.3 Difficulties

A third of respondents stated that they could not exercise either simply saying 'can't exercise' or because of pain, mobility or fatigue. A significantly higher BMI was found for this group. Expending more energy in physical activity would help reduce weight; likewise a higher degree of disablement would make exercising more difficult. However, this has been categorized as a belief as many respondents with similar polio scores did find exercise possible and as a preliminary statistical analysis showed no higher polio score for the 'can't exercise' group. The outcomes from the PPS rehabilitation programme (Davidson et al., 2009)and others presented at the most recent European polio conference show that exercise and beneficial physical activity can often be increased (Tersteeg et al., 2011, September). This points to the possibility that the behaviours of some who say they cannot exercise and give this reason for a poorly controlled weight may be restricted by a belief that is not entirely valid. The research by Weil et al. (2002) over a wide range of disabilities showed that those with lower extremity mobility limitations not only has the highest risk of obesity but also the lowest likelihood of attempting weight loss, lending weight to the hypothesis that this belief is invalid and should be challenged. The restricted behaviours could be learned as part of childhood adaptation to disability in response to the culture at the time or repeated failures in attempting 'conventional' exercise (i.e. recommendation for 150 minutes of moderate activity per week, or the target of increasing heart rate) without the necessary support. The negative reaction to messages on TV and in magazines on the need to exercise was evidenced by the emotion in the quotes under the theme of external messages.

Evidence has been found by NICE and data from the NWCR to show that people can successfully manage weight by diet alone and so the 'can't exercise' belief should

not be linked automatically to unavoidable overweight (National Institute for Health and Clinical Excellence, 2011; Ogden et al., 2012)

Less prevalent beliefs reported include that weight increase is due to ageing or inherited family traits. In a very limited and short-term prospective study,Wamsteker et al. (2005) found a small association with degree of weight loss and belief in a physical origin of obesity, showing that beliefs can affect outcomes. Due to the importance of physical activity not just for weight management but also for health and socialisation, a rigorous study examining these very preliminary indications in more detail would be very important.

Two of the most common sub-themes under 'dealing with food' were comfort eating and nutritional adequacy. The relation of food to mood and as a reward appears in studies of weight management in the wider population (Sawkill et al., 2012). In that study, participants also reported using food to deal with difficult situations and emotions. Giving that the present group studied are all disabled and many expressing strong negative emotions, it is not surprising that emotional eating is a factor. This may also link to the importance of social dining as a leisure activity, perhaps of increased importance for this study group due to the difficulty of participating in active hobbies. Addressing the 'can't exercise' belief in order to increase physical activity and active pastimes may also help in this area.

Several viewed that the low level of calorie intake necessary to maintain or reduce weight led to problems such as feeling unwell or unenergetic. This low level was judged in some cases to be unsustainable and incompatible with an acceptable quality of life. This links to the conclusions discussed in relation to success strategies

and very low calorie diets. Specific information on nutrition could help those who feel they cannot keep to an optimum eating plan for managing weight.

An unexpected theme that emerged related to the impact of weather on weight, both from seasonal and climatic variations in temperature. The impact of cold on polio survivors is documented in terms of increased pain and reduced function (Farbu et al., 2006). Weight gain due to overindulgence and reduced physical activity over the winter holiday season has been studied in the US (Cook, Subar, Troiano, & Schoeller, 2012; Phelan et al., 2008). The new link of weather on weight in polio survivors from this study was attributed to several causes in addition to holiday season indulgence. One respondent noted reduced activity due to being housebound by severe winter weather. Fear of falling on icy surfaces is likely to more strongly affect physically unstable people. Another commented on eating more in order to keep warm. Given the difficulty of losing weight, this study identifies winter as a high risk time for weight management.

5.3.1 Support

Absence of support was reported by some successful and unsuccessful weight managers, mostly in relation to the availability of informed professionals. This is a theme that was prevalent in previous polio survivor surveys (Polio Survivors Network, 2011).

The study by Burke et al. (2008) found that losing weight on one's own by changing intake and activity was the most popular, but that a significant fraction wanted the help of a group or medical professional. This variation in support level preference is also borne out by the cluster analysis carried out on the US National Weight Control Registry by Ogden et al. (2012). The choice of group support or DIY varied between

the four different clusters of successful weight maintainers. Data from NICE evidence reviews and from secondary analysis of NHANES data showed that weight loss programmes and group support were more strongly associated with success than individual methods (National Institute for Health and Clinical Excellence, 2011; Nicklas et al., 2012).

This study shows that a significant number of respondents also would like support either from weight management groups or health professionals. However, many feel this is not available and the knowledge level of polio survivor needs is still very low. One factor that may impact this feeling that support is not available is the length of time that support is required. Polio disablement is a lifetime condition, also data from the NWCR shows that it can take over five years for lifestyle changes for weight management to embed (Wing & Phelan, 2005). The literature search for weight management programmes showed that the needs of physically disabled people and polio survivors in particular are not well represented despite the inclusion of diet and weight management in the NHS pathway for PPS rehabilitation (NHS Map of Medicine, 2011). Other issues include the need for special weighing scale and difficulties with transport to groups.

Even those who do it themselves still make use of published information from the web or books. British Polio and other support organizations have produced literature specific to polio, but this could usefully be extended to address issues emerging from this study such as low nutrition levels and a belief that exercise is not possible.

5.4 Limitations

This exploratory study has unearthed many important points that require further research to make confident conclusions.

Use of a questionnaire as a qualitative research tool is more limited than use of a structured interview as there is no mechanism for further exploration of themes that arise within the study. The very general questions asked did allow respondents to volunteer information they felt important, but it is not possible to prompt for missing information. For example, this has limited interpretation of the sub-theme on inability to exercise as exploring the meaning behind it would require a semi-structured interview. Hence any statistical analysis of prevalence has to be viewed as very preliminary.

The self-reported information on weight related co-morbidities (Question 10) is inadequate for comparison to the measured population levels from the Health Survey for England, though it may indicate a real effect.

Searching for evidence of inclusion of physically disabled people's needs in PCT or local authority weight management programmes was limited by available published literature. This would require a specific audit.

The methods of dissemination via the British Polio website and magazine did allow a large number of people to be accessed. However, the membership of this organization represented less than 10% of UK polio survivors.

Another difficulty in using a questionnaire was that proving trustworthiness of the data was limited (Pitney & Parker, 2009). Triangulation techniques such as using more than one method of data collection or another researcher to analyse the responses were outside the scope and timescale of this study as were peer debriefing and participant checks. The comparison of findings with the literature search did provide another data form for cross-checking.

One factor that may affect the accuracy of activity data is that some people had concerns about revealing how much they walked and the risk of the information affecting Disabled Living Allowance eligibility (verbal communication at a group meeting).

Three respondents had problems, not with weight gain, but with weight loss and anorexia. This percentage is consistent with prevalence of underweight in the general population. This study was more targeted at weight gain; coupled with the low numbers of respondents in this category, no conclusions can be drawn.

Chapter 6. Conclusions and future research

6.1 Conclusions

This exploratory study has provided evidence that weight management is an issue for polio survivors, with many respondents unable to maintain a healthy weight and others, while being more successful, exercising extreme control to achieve goals. It is directly linked by many to mobility and self-image.

There is an indication that a belief that exercise is not possible may be restricting some from attempting or succeeding with weight loss.

Many polio survivors are successfully managing their weight using the behaviours common to general population studies. Most use self-directed approaches.

There is little evidence of weight management programmes that target the low mobility population group, despite the policy direction that mandates its provision. Many respondents would like more relevant professional and group support.

Most respondents had difficulty with weight control. Some respondents are reporting calorie intake levels low enough to risk nutritional deficiency. Some feel that they cannot keep to a low enough calorie intake to manage their weight.

The guidelines on ideal body weight promoted for the general population may not be applicable to this group due to the impact of muscle loss on body composition. Calculated energy intake needs may also not be relevant due to lower activity levels and possibly low levels of metabolically more active tissue. The wide promotion of these guidelines is reported as causing stress for people who feel unable to comply.

6.2 Future research

Several areas merit further research.

The topic of barriers to exercise and activity in polio survivors could usefully be explored in more depth using semi-structured interviews with a representative cross-section. The study design should aim to also reach people who are not British Polio members.

This study indicated that BMI and disablement from polio did not correlate. A rigorous study employing validated disablement and activity scales is necessary to determine whether or not this is the case. This could include a validated nutritional analysis to assess the prevalence of under-nutrition.

A clinical study of health status would determine the typical health status of polio survivors. Respondents to this survey reported levels of co-morbidities lower than measured population levels, which if borne out would imply that many are not being treated for modifiable risk factors. This data may already exist in the records of post-polio clinics and may only require a secondary analysis study.

A body composition study is required to determine BMI risk thresholds for this population group; only two small studies in non-Europeans have been found. This would require gold standard body composition measurements (Heyward & Wagner, 2004).

Of wider applicability is the apparent absence of weight management programmes targeted at people with physical disabilities. A focused audit of services within one or two PCT regions should proactively investigate the level of provision.

6.3 Application to clinical practice

Some actions can be taken on the existing strength of the results.

Practitioners should take into account the body composition of polio survivors when making recommendations for target body weights and calorie intake. People with this condition may need a detailed nutritional assessment that goes into greater depth than the general population guidelines.

A NICE project team is currently devising guidelines on lifestyle weight management services for managing overweight and obesity in adults (NICE, 2012). The clinical input from primary care stakeholders should ensure that the needs of disabled people are fully included.

Use of the NICE BMI thresholds for surgical intervention may not be appropriate for this population as polio survivors may present below the BMI threshold but still have very high body fat percentage and little means of reducing weight. In common with the needs of people with spinal cord injuries, (Rajan et al., 2008), the role of surgery for this population should be examined.

6.4 The role of Polio Support Groups

Several support groups are active in the UK and Ireland;

British Polio, (http://www.britishpolio.org.uk/)

the Polio Survivors Network, (http://www.poliosurvivorsnetwork.org.uk/),

the Scottish Post-polio Network (http://www.sppn.org.uk/),

and the Northern Ireland Polio Fellowship, (http://www.polio-ni.org/).

These organizations have a role to play in disseminating information and encouraging healthy behaviours. British Polio produces factsheets on key topics.

This could be extended to include information on low nutrition levels for those keeping to very low calorie diets. It could also help in the promotion of feasible physical activity.

The organization does work to increase medical professional's knowledge of PPS. This study shows that continuing effort is still required and that PCT and local authority weight management programme developers could usefully be approached to help improve inclusiveness for polio survivors. This action would also be of benefit to other physically disabled people and could be co-ordinated with other support organizations (for example, those supporting people with spinal cord injuries, multiple sclerosis or arthritis).

British Polio as a registered stakeholder is well positioned to input to the NICE guidelines on weight management services under development.

6.5 Transferability

Results from this study are likely to be transferable to other physically disabled people with low mobility. In particular it may be relevant to those whose disability has occurred in childhood.

Chapter 7. References

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Appendix 1. Examples of returned Pubmed searches

Search on weight management or loss and polio

PubMed

Display Settings: Summary, 20 per page, Sorted by Recently Added

Clipboard: 13 Remove all items

1. Glenohumeral tuberculous arthritis complicated with beta haemolytic streptococcus: An extraordinary rare association: A case report.
   Rashid RH, Sarwar MU, Akhtar J, Noordin S.
   Int J Surg Case Rep. 2012;3(5):164-6. Epub 2012 Jan 23.
   PMID:22382034[PubMed - in process] Free PMC Article

2. A need for careful evaluation of endotoxin contents in acellular pertussis-based combination vaccines.
   Kataoka M, Ochiai M, Yamamoto A, Horiuchi Y.
   Biologicals. 2012 Jan;40(1):49-54. Epub 2012 Jan 10.
   PMID:22239994[PubMed - indexed for MEDLINE]

3. Comparative safety, immunogenicity, and efficacy of several anti-H5N1 influenza experimental vaccines in a mouse and chicken models (Testing of killed and live H5 vaccine).
   Gambaryan AS, Lomakina NF, Boravleva EY, Kropotkina EA, Mashin VV, Krasilnikov IV, Klimov AI, Rudenko LG.
   Influenza Other Respi Viruses. 2012 May;6(3):189-95. doi: 10.1111/j.1750-2659.2011.00291.x. Epub 2011 Sep 29.
   PMID:21951678[PubMed - indexed for MEDLINE]

4. Approved and investigational uses of modafinil : an evidence-based review.
   Kumar R.
   Drugs. 2008;68(13):1803-39. Review.
   PMID:18729534[PubMed - indexed for MEDLINE]

5. EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force.
   Farbu E, Gilhus NE, Barnes MP, Borg K, de Visser M, Driessen A, Howard R, Nollet F, Opara J, Stalberg E.
   Eur J Neurol. 2006 Aug;13(8):795-801.
   PMID:16879288[PubMed - indexed for MEDLINE]

6. Respiratory failure in a patient with antecedent poliomyelitis: amyotrophic lateral sclerosis or post-polio syndrome?
   Terao S, Miura N, Noda A, Yoshida M, Hashizume Y, Ikeda H, Sobue G.
   Clin Neurol Neurosurg. 2006 Oct;108(7):670-4. Epub 2005 Sep 13.
   PMID:16165287[PubMed - indexed for MEDLINE]

7. Post-Polio Syndrome.
   Jubelt B.
   Curr Treat Options Neurol. 2004 Mar;6(2):87-93.
   PMID:14759341[PubMed - as supplied by publisher]

8. Is bariatric surgery effective in the treatment of the neurological motor deficit syndromes?
   Flanagan L Jr
   Obes Surg. 1997 Oct;7(5):420-3.
   PMID:9730498[PubMed - indexed for MEDLINE]

9. Child health surveillance. Surveillance of the child under 5.
   Bantock H, Modell M.

Occas Pap R Coll Gen Pract. 1992 Dec;(58):79-88.
PMID:1285363[PubMed - indexed for MEDLINE] Free PMC Article

☐ Exotic diarrhoeal problems and poliomyelitis.
10. Cubbon I.
Practitioner. 1989 Jun 22;233(1471):927-31.
PMID:2594659[PubMed - indexed for MEDLINE]

☐ Symptoms and clinical impressions of patients seen in a postpolio clinic.
11. Agre JC, Rodriquez AA, Sperling KB.
Arch Phys Med Rehabil. 1989 May;70(5):367-70.
PMID:2719039[PubMed - indexed for MEDLINE]

☐ Fleur-de-lis abdominoplasty.
12. Dellon AL.
Aesthetic Plast Surg. 1985;9(1):27-32.
PMID:3158172[PubMed - indexed for MEDLINE]

☐ Renal hemodynamic studies in patients with extensive paralysis; the influence of weight loss, muscle atrophy, and immobilization.
13. DAESCHNER CW, MOYER JH, PFEIFFER EM.
J Chronic Dis. 1958 Jan;7(1):43-51. No abstract available.
PMID:13491676[PubMed - OLDMEDLINE]

Search on Obesity and Polio

PubMed

Display Settings: Summary, 50 per page, Sorted by Recently Added

Clipboard: 21 Remove all items

1. Home mechanical ventilation: a Canadian Thoracic Society clinical practice guideline.
McKim DA, Road J, Avendano M, Abdool S, Cote F, Duguid N, Fraser J, Maltais F, Morrison DL, O'Connell C, Petrof BJ, Rimmer K, Skomro R; Canadian Thoracic Society Home Mechanical Ventilation Committee.
Can Respir J. 2011 Jul-Aug;18(4):197-215.
PMID:22059178[PubMed - indexed for MEDLINE] Free PMC Article

2. Body composition assessment in Taiwanese individuals with poliomyelitis.
Chang KH, Lai CH, Chen SC, Hsiao WT, Liou TH, Lee CM.
Arch Phys Med Rehabil. 2011 Jul;92(7):1092-7.
PMID:21704790[PubMed - indexed for MEDLINE]

3. Comorbidity profile of poliomyelitis survivors in a Chinese population: a population-based study.
Kang JH, Lin HC.
J Neurol. 2011 Jun;258(6):1026-33. Epub 2011 Jan 30.
PMID:21279517[PubMed - indexed for MEDLINE]

4. [Follow-up of patients with home mechanical ventilation: experience in Geneva, Switzerland].
Pasquina P, Bourqui P, Farr P, Janssens JP.
Rev Med Suisse. 2008 Nov 19;4(180):2518-20, 2522-4. Review. French.
PMID:19127896[PubMed - indexed for MEDLINE]

5. Hormone replacement therapy and health behavior in postmenopausal polio survivors.
Kalpakjian CZ, Riley BB, Quint EH, Tate DG.
Maturitas. 2004 Aug 20;48(4):398-410.
PMID:15283932[PubMed - indexed for MEDLINE]

6. Shaping the future of global health.
Haines A.
Bull World Health Organ. 2003;81(12):855. Epub 2004 Mar 1. No abstract available.
PMID:14997236[PubMed - indexed for MEDLINE] Free PMC Article

7. Cardiac risk factors in polio survivors.
Gawne AC, Wells KR, Wilson KS.
Arch Phys Med Rehabil. 2003 May;84(5):694-6.
PMID:12736884[PubMed - indexed for MEDLINE]

8. Evaluation of health-related quality of life using the MOS 36-Item Short-Form Health Status Survey in patients receiving noninvasive positive pressure ventilation.
Windisch W, Freidel K, Schucher B, Baumann H, Wiebel M, Matthys H, Petermann F.
Intensive Care Med. 2003 Apr;29(4):615-21. Epub 2003 Mar 5.
PMID:12618917[PubMed - indexed for MEDLINE]

9. Changing patterns in long-term noninvasive ventilation: a 7-year prospective study in the Geneva Lake area.
Janssens JP, Derivaz S, Breitenstein E, De Muralt B, Fitting JW, Chevrolet JC, Rochat T.

Chest. 2003 Jan;123(1):67-79.
PMID:12527605[PubMed - indexed for MEDLINE]

☐ Recent advances: Paediatrics.
10. Jain A, Davis MM.
BMJ. 2001 Jun 16;322(7300):1469-72. Review. No abstract available.
PMID:11408306[PubMed - indexed for MEDLINE] Free PMC Article

☐ Is bariatric surgery effective in the treatment of the neurological motor deficit syndromes?
11. Flanagan L Jr.
Obes Surg. 1997 Oct;7(5):420-3.
PMID:9730498[PubMed - indexed for MEDLINE]

☐ Quality of life of patients under home mechanical ventilation for restrictive lung diseases: a comparative evaluation with COPD patients.
12. Janssens JP, Penalosa B, Degive C, Rabeus M, Rochat T.
Monaldi Arch Chest Dis. 1996 Jun;51(3):178-84.
PMID:8766189[PubMed - indexed for MEDLINE]

☐ Estimation of chronic disease load in a rural area of Haryana.
13. Singh A.
J Indian Med Assoc. 1995 Jul;93(7):268-70.
PMID:8576591[PubMed - indexed for MEDLINE]

☐ Management of post-polio respiratory sequelae.
14. Bach JR.
Ann N Y Acad Sci. 1995 May 25;753:96-102.
PMID:7611664[PubMed - indexed for MEDLINE]

☐ Fleur-de-lis abdominoplasty.
15. Dellon AL.
Aesthetic Plast Surg. 1985;9(1):27-32.
PMID:3158172[PubMed - indexed for MEDLINE]

☐ Differential diagnosis of chronic respiratory insufficiency.
16. Baum GL.
Med Clin North Am. 1973 May;57(3):623-35. Review. No abstract available.
PMID:4121735[PubMed - indexed for MEDLINE]

☐ The syndrome of chronic alveolar hypoventilation.
17. Fishman AP.
Bull Physiopathol Respir (Nancy). 1972 Sep-Oct;8(5):971-80. No abstract available.
PMID:4657874[PubMed - indexed for MEDLINE]

☐ Body composition in relation to disease.
18. Steinkamp RC.
Am J Public Health Nations Health. 1968 Mar;58(3):473-6. Review. No abstract available.
PMID:4868645[PubMed - indexed for MEDLINE] Free PMC Article

☐ [Thoraco-abdominal mechanics].
19. Colinet-Lagneaux D, Troquet J.

☐ [HYPOTHALAMIC SYNDROMES FOLLOWING POLIOMYELITIS].
20. IURASOG G, MIHAILA M.
J Med Lyon. 1964 Nov 5;45:1887-911. French. No abstract available.
PMID:14230079[PubMed - indexed for MEDLINE]

☐ [POST-POLIOMYELITIS HYPOTHALAMIC SYNDROMES].
21. IURASOG G, MIHAILA M.
Stud Cercet Inframicrobiol. 1964;15:359-76. Romanian. No abstract available.
PMID:14235209[PubMed - indexed for MEDLINE]

Appendix 2. Audit data of Weight Management Programmes for four Regions

Table 1. Audits of NHS funded weight management programmes

Region	Year, Audit	Number of adult WMP	Types	Intervention length	evaluation	Disability considered	reference
East Midlands PHO	2011 2nd audit	9	Mostly unique types including mixtures of physical activity, diet, behavior 1 use of Counterweight No mention of commercial referral	12 weeks (5) > 1yr (6)	8 using SEF	2 include physical disabled as target group	(Roberts & Marvin, 2011)
North East PHO	2010 3rd audit	33	Range of types, many unique including mixtures of physical activity, diet, behavior, goals 10 referral schemes to Weight Watchers, Slimming World and Rosemary Conley	≤15 weeks where given	70% using SEF, but not fully compliant	No mention of physically disabled	(NEPHO, 2010)
East of England	2011 1st audit	27	24 distinct types, 21 unique	≤17 weeks 84%	No scheme 100% SEF compliant	1 targeted physically disabled	(Head, 2011)
London	Review	76	Diverse schemes from NHS, local authority, small scale providers, commercial	Not covered	SEF required in contracts, but compliance not usually checked	No mention of physically disabled	(Sim & Ahmad, 2010)

Appendix 3. Table of Published Evaluations for UK Weight Management Programmes

programme	Year, report	Number	Types	length	evaluation	Disability considered	reference
Shape-up Anglian Community Enterprise	2011 Brief report of use by North East essex PCT	581 at 68 courses	Lifestyle, behavior change based, covering diet, activity Programme developed and overseen by Weight Concern, UK Charity Group sessions	8 weeks	Average weight loss cited as 2.8kg, no statistical analysis	No mention	("Shape Up (Weight Concern) Anglian Community Enterprise annual report summary," 2011)
Lite-4-Life NHS Stockton-on-Tees	2011 Detailed report	120 74 completers	Diet, lifestyle, some behavior change 1 to1 and group session	10 weeks 18 week follow-up	38% of completers lost >5% body weight (no p value given) 54% of these continued to lose weight after further 18 weeks	Mentioned as “large proportion had long term illness or disability” One wheelchair user raised issue relating to exercise	(Hanna & Wilburn, 2011)
Wirral PCT Lifestyle and Weight management programme	2009 Preliminary report, economic evaluation	3810	Range of 1 to one and group sessions depending on BMI Based on diet, physical activity, behavior change	12 weeks with 9 monthly follow-ups	At 12 weeks, % of body lost 2.56% females, 3.6% males ($p<0.001$ for both) Data not given for the 20% who completed 1yr follow-up	Disability data only as ‘sick/disabled’ status (9.7%) or ‘requiring disabled access’ (10.2%)	(Health Economics Unit, 2009)
Hertfordshire Weight Management Pilot	2011 Evaluation report	1812 923 completers Across 24 sites	Set protocol Mostly 1-1 delivery Covering diet, activity and behavior change	12 weeks	37% of completers lost >5% body weight, varying across site between 4% and 63% of completers 91% lost some weight	No mention	(NHS Hertfordshire, 2011)
Glasgow and CLyde Weight Management Service	2011 Published peer reviewed evaluation of first phase	2156 809 completers	Diet, physical activity, lifestyle, behavior change including range of cognitive approaches Group sessions	16 weeks (Phase 1)	35% of completers lost more than 5% initial body weight	No mention	(Morrison et al., 2011)

programme	Year, report	Number	Types	length	evaluation	Disability considered	reference
Camden Weight Loss Programme	2012 Published peer reviewed RCT	381 over 23 GP practices	Diet, physical activity, lifestyle, goals, monitoring Note: control group was directed to 'usual weight management care' which could include dieticians, exercise referral, weight loss drugs and other treatment so cannot be viewed as a no treatment comparison	1 year, 14 sessions at reducing rate	No sig difference in weight loss between intervention and control: excluding those who took weight loss drugs gave a weight loss of 1.72kg for the intervention (0.29-3.14, p=0.02) Higher proportion in intervention group lost >5% initial weight (OR 2.68, p=0.03)	No mention	(Nanchahal et al., 2012)
NHS Central Lancashire Pharmacy Weight Management Service	2010 Service evaluation	58 Reducing to 40 at 12 weeks, 5 at end	1-1 motivational interviewing, lifestyle change based on diet and physical activity	1 yr Sessions at reducing rate	Average weight loss 2.06 kg (p<0.05) at 12 weeks (40 people), 2.88 kg at intervention end (5 people)	No mention	(Vohra, 2010)
Counterweight Programme	2012 Published peer reviewed evaluation	6715 from 184 UK sites 1880 completers	Range of approaches depending on stage of change; based on diet, activity, behaviour, goal setting (spinout by Robert Gordon University)	12 weeks, 4 follow-ups to 12 months	At 12 months, 35.2% weight loss >5% initial weight (32.2-38.4 95% CI)	No mention	(Counterweight Project Team, 2012)
Commercial programmes							
Slimming World	2012 published peer reviewed service audit several authors Slimming world employees	4754 UK Primary care referral for 2 x 12 week sessions	Diet and physical activity Weekly group sessions	24 weeks	Mean weight change at 24 weeks -8.6% (s.d. 5.3%) initial weight, mean attendance 21.3 (s.d. 3.2) sessions 76.3% attended 20 out of 24 sessions	No mention	(Stubbs et al., 2012)

programme	Year, report	Number	Types	length	evaluation	Disability considered	reference
Weight Watchers	2011 Published peer reviewed RCT Funded by Weight Watchers Int.	377 230 completers (396 controls on standard care, 214 completed) From 30 GP practices, 6 in UK	Weekly group meetings, based on diet, behaviour and physical activity	12 months	Mean weight change at 12 months for completers -6.65 kg (SE 0.43) for the intervention, -3.26 kg (SE 0.23) for controls, difference -3.16 kg (-4.23 to -2.11, 95% CI, p<0.0001) (estimate of difference at 12 weeks approximately 2kg more for intervention, read from graph)	'People with orthopaedic limitations preventing participation in physical activity' were excluded	(Jebb et al., 2011)
Nutracheck	2011 Published peer reviewed retrospective analysis	3621	Web-based, commercial subscriber self-help Food and activity diaries and information, forum support	Varied from 28 to 1284 days, mean 169 days women, 186 days men	Mean weight loss 4.5 (s.d. 5.5) kg women, 5.5 (s.d.5.9) kg for men, p<0.001	No mention	(Johnson & Wardle, 2011)
Commercial programmes commissioned by the NHS							
Healthy Choices (Dorset, NHS)	2011 Published peer reviewed prospective cohort Service evaluation	2456	Qualifying participants referred given vouchers for either Weight Watchers or Slimming World, no control or comparison group NB aim BMI>28, but not applied fully	12 weeks	44% of all starters had >5% weight loss at 12 weeks Mean weight loss 4.68 kg (s.d. 3.8, p=0.0001) No significant difference in weight loss between providers	No mention	(Lloyd & Khan, 2011)

programme	Year, report	Number	Types	length	evaluation	Disability considered	reference
Lighten Up South Birmingham PCT	2011 Published peer reviewed RCT	658	Participants randomly assigned to Weight Watchers, Slimming World, Rosemary Conley, dietetics led programme, GP 1-1 counselling, pharmacy 1-1 counselling, and free choice. Comparator group given leisure centre vouchers	12 weeks Follow-up at 1yr	12 weeks:- All groups lost significant amounts of weight Only the commercial groups lost significantly more than the comparator (e.g. for WW, 2.5kg more, 0.8-4.2 95% CI) In commercial groups, 35-46% lost >5% initial weight compared to 15-21% in primary care groups and 22% in comparator group 1 year follow-up: only Weight Watchers group had significantly more weight loss than comparator Primary care costs around 25% higher than commercial providers	No mention	(Jolly et al., 2011)

Appendix 4. Letter of Approval from Ethics Committee

University of Chester
Faculty of Applied Sciences
Research Ethics Committee

Tel 01244 511740
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14th March 2012

Dear Frances,

Study title: **Experiences and Evaluation of Weight Control Approaches among Polio survivors.**
FREC reference: **624/12/FQ/CS**
Version number: **1**

Thank you for sending your application to the Faculty of Applied Sciences Research Ethics Committee for review.

I am pleased to confirm ethical approval for the above research, provided that you comply with the conditions set out in the attached document, and adhere to the processes described in your application form and supporting documentation.

The final list of documents reviewed and approved by the Committee is as follows:-

Document	Version	Date
Application Form	1	January 2012
Appendix 1 – List of References	1	January 2012
Appendix 2 – C.V. for Lead Researcher	1	January 2012
Appendix 3 – Letter of Invitation to Participants	1	January 2012
Appendix 4 – Participant Information Sheet	1	January 2012
Appendix 6 – Permissions – British Polio 'Bulletin'	1	January 2012
Appendix 7 – Interview Schedule	1	January 2012
Appendix 8 – Questionnaire	1	January 2012
Appendix 11 – Questionnaire Matrix	1	January 2012
Response to FREC request for further information and clarification		March 2012
Appendix 3 – Letter of Invitation to Participants	2	March 2012
Appendix 4 – Participant Information Sheet	2	March 2012
Appendix 6 – Permissions – British Polio 'Bulletin'	2	March 2012
Appendix 8 – Questionnaire	2	March 2012

With the Committee's best wishes for the success of this project.

Yours sincerely,

Cynthia O'Burek

Prof. Cynthia Burek
Chair, Faculty Research Ethics Committee
Enclosures: *Standard conditions of approval.*

C.c. *Supervisor/FREC Representative*

FREC B
Approval letter – 2011/12

Appendix 5. Survey Questionnaire and PIS

University of Chester

Participant information sheet

Experiences and Evaluation of Weight Control Approaches among Polio Survivors

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?
The aim is to investigate the experiences of people with low mobility with weight control over the long term. I have selected polio survivors as I also contracted polio which has made me interested in health issues with this condition. I want to determine how much of a problem weight management, both for over- and under-weight, is for this group. I also aim to look at the range of approaches taken, both by individuals and those recommended for them by health professionals and to see how successful these are felt to be by the people using them.

Why have I been chosen?
You have been invited to take part because you are a polio survivor.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to complete a questionnaire. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in any way.

What will happen to me if I take part?
If you decide to take part, please fill in the questionnaire attached and return by the stamped addressed envelope provided, or complete online at https://www.surveymonkey.com/s/KGXFRKR. This should take about 15 minutes. You will also be asked in the questionnaire if you are willing to be contacted by telephone for further details on your personal experiences with weight control (taking about 20 minutes) - this information will be used as case studies to examine in more detail the issues of weight management with low

contacted you will be asked for contact details. If you are contacted for a telephone interview, you will be asked if you agree to the interview being recorded.

What are the possible disadvantages and risks of taking part?
There are no disadvantages or risks foreseen in taking part in the study.

What are the possible benefits of taking part?
As a polio survivor it is possible that you may welcome the opportunity to share and discuss your views and experiences with other polio survivors. By taking part, you will be contributing to the understanding of the issues through sharing your views, which will hopefully benefit people in the future.

What if something goes wrong?
If you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Professor Sarah Andrew, Dean of the Faculty of Applied Sciences, University of Chester, Parkgate Road, Chester, CH1 4BJ, 01244 513055.

Will my taking part in the study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential so that only the researcher carrying out the research will have access to such information.

What will happen to the results of the research study?
The results will be written up into a dissertation for my final project of my MSc. Individuals who participate will not be identified in any subsequent report or publication.

Who is organising the research?
The research is conducted as part of a MSc in Exercise & Nutrition Science within the Department of Clinical Sciences at the University of Chester. The study is organised with supervision from the department, by Frances Quinn an MSc student.

Who may I contact for further information?
If you would like more information about the research before you decide whether or not you would be willing to take part, please contact:

Frances Quinn - email 10198189@chester.ac.uk
Return address for survey - Frances Quinn
Dept. Of Clinical Sciences
University of Chester,
Chester
CH1 4BJ

Thank you for your interest in this research.

Experiences with Weight Control among polio survivors

Your experience with polio

1. At what age did you contract polio?

***2. What age are you now?**

***3. How did polio affect you physically? please tick the boxes that most closely describes how polio affected you physically.**

	Nothing diagnosed	Slightly	Moderately	Extensively
Arms	○	○	○	○
Legs	○	○	○	○
Trunk	○	○	○	○

About your mobility and health

***4. How mobile are you? Tick the most relevant**

	motorised wheelchair	Self-propelled wheelchair	walk with walking sticks or wheeled frame/rollator	walk without aids
How I get about	○	○	○	○

***5. If you are able to walk, with or without aids, how far can you walk?**

	Around the house	10-15 mins close to home (e.g. around a garden)	15-90 mins round shops or garden area	longer
tick the most relevant	○	○	○	○

6. Has your mobility changed since you stabilised after recovering from Polio? Please tick.

○ Yes

○ No

7. If yes, please describe roughly how and when.

Experiences with Weight Control among polio survivors

***8. How would you describe your present activity level?**

	Sedentary (e.g. spend most of time sitting, using computer, watching TV, reading/hobbying, minimal household, garden or work activities)	**Low activity** (e.g. spend some time on light housework or gardening, moving around slowly, some light, gentle, active recreation)	**Medium activity** (e.g. regular physical tasks at home, in garden or at work, regular moderate active recreation such as walking)	**High activity** (e.g. spend most of time moving, often in activity that comfortably raises breathing and heart-rate such as swimming or basketball)
tick most relevant	◯	◯	◯	◯

Your health

9. How would you describe your present state of health?

	good	fair	poor
tick most relevant	◯	◯	◯

***10. Do you have any other medical conditions which have been diagnosed as likely to be related to weight? for example, high blood pressure, high cholesterol, type II diabetes.**

- ◯ No
- ◯ high blood pressure
- ◯ high cholesterol
- ◯ type II diabetes

Other (please specify)

Experiences with Weight Control among polio survivors

Your weight management experience

This section asks for information on your current and past weight.
Questions are also asked about the methods you have used to manage your weight and about the difficulties and successes you have experienced

***11. What are your body measurements?**

Height .....(please say if in feet and inches or metres)

Waist circumference.... (please say if inches or cms - to measure, place tape halfway between the top of your hip bone and the bottom of your rib cage, breathe out naturally and note the measurement)

Hip circumference .....(to measure, place the tape at the fullest part of your hips and note the measurement)

Present weight .....(say if kg or stones/lbs)

Is there anything that might make these measurements unreliable? (for example, spinal curvature or short limbs)

12. How has your weight varied during your life?

What is the lightest weight you have been as an adult and at what age?

What is the heaviest weight you have been as an adult and at what age?

13. How do you feel about your weight?

Experiences with Weight Control among polio survivors

***14. Have you ever tried to lose weight?**

	never	once or twice	2-5 times	more than 5 times	constantly try to manage weight
tick most relevant	◯	◯	◯	◯	◯

***15. Have you ever experienced difficulty in maintaining a healthy weight?**

◯ yes

◯ no

***16. If so, what difficulties did you experience?**

Weight management methods used

***17. If you have tried approaches to lose weight, prevent weight gain or maintain a healthy weight, what methods have you used? tick all that you have used**

	used once	used a few times	used many times
Nutritional assessment and prescribed diet	◯	◯	◯
Self-chosen diet	◯	◯	◯
Physiotherapist assessment and prescribed exercises	◯	◯	◯
Exercise classes	◯	◯	◯
Self-directed exercise	◯	◯	◯
Medications	◯	◯	◯
Surgery	◯	◯	◯

Other (please specify)

Experiences with Weight Control among polio survivors

***18. Do you feel any of these methods worked well for you personally?**

- ◯ No
- ◯ yes

If yes, which ones worked

***19. What aspect of these methods made them successful or unsuccessful for you?**
(possible aspects are, the interaction with informed and helpful professionals, joining in with other people who have similar difficulties, the ability to talk by yourself with a professional, the provision of information on diet and exercise, allowing time in your day to put plans into action, medical help)

Experiences with Weight Control among polio survivors

20. Please add any additional comments you feel are relevant

Further contact

In order to further explore some of the successful methods and the problems people have had, I would like to interview a few people to explore their experiences in more depth.
This is only to illustrate some of the common issues that may be raised in the responses to the questionnaire - all personal information will be confidential

21. Would you be willing to be to be contacted for further information on your experiences with weight control via a short, informal telephone interview
(recording the interview helps to make analysis of the responses easier - interviews would only be recorded with the person's agreement at the start of the phone call)

- ◯ yes
- ◯ no

22. If you are happy to be contacted, please provide contact details below

Name	
telephone number	
email (if available)	
address (if you would like to be contacted by post before the telephone call)	

Thank you for your help and sharing your experiences.

Thank you for taking the time to share your experiences and complete this survey.

Appendix 6. Polio Bulletin Article

Final Version of Article: 4/4/12

Share your experiences - they could hold weight for others.....

Invitation to join a study of experiences of polio survivors with weight management

Having limited mobility like many polio survivors makes it difficult to maintain weight within healthy guidelines - neither too much nor too little. It is possible that people with this issue may find that weight management is a bigger problem for them than the average person. Bulletin readers, as a very determined bunch, will have tried many ways to deal with this issue - your experiences of what works best could help both fellow polio survivors and health professionals provide better advice and support to improve well-being. Sharing your own stories can also help others to see that they are not alone in their difficulty - as this magazine proves time and time again.

Hardly a day goes past without us hearing something about the need to maintain a healthy weight. TV reality shows, magazine articles, radio talk programmes, friends and colleagues all approach the issue of weight control, along with many science studies. It is also big business, with slimming clubs, food producers and books selling a continuing array of exercise or diet products.

However, despite the wide availability of advice and help, for many people, it is difficult to keep to a healthy weight in an increasingly sedentary environment with easy access to lots of food. How much more difficult is it when physical limitations restrict the ability to exercise? People with long term mobility problems are also more affected by carrying too much weight, giving increasing pain and making it more difficult to tackle the activities of daily life.

I am studying for an MSc in Exercise and Nutrition Science at the University of Chester and am doing a research project in this area. Because of my own experiences with health as a polio survivor I am interested in how people with low mobility can best manage their weight. I want to hear from other polio survivors about their experiences with weight over their lifetime - this includes people of all weight ranges and mobilities. The aim is to see what experiences people have, which approach seems to work best and how much of an impact low mobility has on their weight.

This information will be used to see how much of an issue it is for polio survivors in comparison to the wider population. The study aims to provide information that will be of use to health professionals. Lastly, it gives an opportunity to share experiences of a sensitive and sometimes stressful subject amongst people with mobility difficulties.

If you are interested in sharing your experiences, please contact me for a questionnaire (address below) - it should take only 20-30 minutes to complete and all responses will be confidential. The questionnaire can also be completed online at https://www.surveymonkey.com/s/KGXFRKR.

The results will be published later in the year online and in the Bulletin.

Thanks in advance for your help.

Frances Quinn

Department of Clinical Sciences
University of Chester
Parkgate Road
Chester
CH1 4BJ
Email: 1019818@chester.ac.uk

Appendix 7. Example line by line coded sheet for Question 13

The text responses to open questions were copied into a Word file and segments colour coded against the research topics.

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
138	bad	1. Bad
137	okay	2. okay
136	I have tried diets but I like my home cooked food too much, and how can I exercise when I get a lot of leg pain. I know I am a few stone over weight, but I am light compared to some people	3. Pain on exercise 4. Food enjoyment 5. Awareness of overweight (few st) 6. Degree compared to others (light) 7. Tried diets
135	trying to get it down	8. trying
134	not happy at all because of my inability to actually lose any weight	9. unhappy 10. unable to lose
133	unhappy, frustrated I know I'm too heavy, I have always been aware of eating healthily and only have breakfast and evening meal and have done for some years now but fail to lose weight	11. unhappy 12. frustrated 13. awareness of overweight 14. aware of eating healthily 15. Fail to lose 16. Controlled intake (B+EM)
132	I don't like it but its hard to lose	17. Don't like 18. Hard to lose
131	Would like to lose about a stone as I have arthritis in my left leg (good leg) & I find it easier to keep mobile the ligher I am	19. Would like to lose st 20. Easier to be mobile if lighter

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
130	I feel very embarassed & unhappy about my weight even though I realise I could be more in control over my diet I obviously comfort eat so only have myself to blame	21. Embarrassed 22. Unhappy 23. Could be more in control 24. Self blame 25. Comfort eat
129	I feel overweight at 12 stone and feel it would be easier to get around if I was slimmer!	26. Awareness of overweight 27. Easier to be mobile if lighter
128	happy. I am concerned, not that I am overweight now, but that I do not want to become overweight	28. Happy 29. Want to avoid OW
127	I feel that I am on the 'overweight' side but not greatly as I signed? some of it as a natural consequence of middle age spread	30. Awareness of overweight 31. Feel some due to middle age spread
126	happy	32. happy
125	I wish i could lose weight I eat a healthy diet	33. wish could lose 34. eat healthily
124	not really happy, it is a bit harder to lose when one gets a bit older. That is why I walk as much as possible	35. not happy 36. hard to lose when older 37. walk as much as possible (limits?)
123	pretty good	38. good
122	to heavy	39. too heavy
121		
120	Very unhappy.	40. unhappy

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
119	OK	41. OK
118	I am having increased problems keeping my weight down as my mobility decreases. I would like to weigh appox 9st 7lbs	42. Would like to lose 43. Harder a mobility reduces
117	worried.	44. worried
116		
115	frustrated ugly fat hopeless However much I try to control my weight I seem to fail. I know I should exercise but this seems to become more and more difficult. I like to swim but the nearest pool is a distance away and i don't drive anymore. I also can't walk far. I have been a weight watcher/ slimmers world /cambridge diet/ diet chef and have recently been refered to the surgery weight clinic which was great to start with but as I go away so much with my husband in our motorhome (when he is working) continuity is a problem for me. I find it very hard to cook meals that are "sensible " for me and pleasing for him. having said that he is very supportive of me and is a constant help and support. however I feel i am letting myself down and hampering his active life style.	45. Frustrated 46. Ugly/fat 47. Hopeless 48. Letting self down 49. Hampering spouse 50. Try to control 51. Difficult to exercise 52. Impact of travelling 53. Hard to cater for self and spouse 54. Tried many approaches 55. Spousal support
114	would like to be slimmer but am happy with who i am and how i look so not a big issue with me	56. Would like to lose 57. Happy with self 58. Looks unimportant
113	I exercise with a rowing machine at home 10 mins a day to keep the weight under control.	59. exercise

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
112	I hate my size, it is very depressing, and like most people who are in severe pain there is no activity that I can do that helps. Swimming would possible help in a warm pool and there is a local swimming pool,but it is mostly used by schools and is quite cool. I don't know how to make myself feel fitter and loose weight, and although I woould want to be 7+ stone again realistically 10 stone would be good. I'm also convinced that the extra weight doesn't help with the joint and muscle pain, my GP suggested short walks each day but, even short walks cause pain.	60. Hate size 61. Depressing 62. Feel affects joints/pain 63. Pain on exercise/activity
111	I'm happy with it and I try to maintain it as I can tell the adverse effect it has when standing or walking if I put on just a couple of pounds	64. Happy 65. Aware of impact on mobility 66. Want to avoid OW
110		
109		
108	I feel I am underweight and am struggling to maintain my weight although I eat healthily and regularly.	67. Underweight 68. Eat healthily
107	would like to be about 62kg	69. Would like to lose
106	I do not worry about it unduly	70. Not worried
105	I would like to loose some.	71. Would like to lose
104	NOT CONCERNED	72. Not worried
103		
102	Now I feel OK about it. It's about the middle of normal on the BFI. Easier to walk around and climb stairs. But still have to be careful as easy to put on again. Have already put on 7 lbs in last few months.	73. OK 74. Aware of impact on mobility 75. Want to avoid OW

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
101	depressed ,I know that is causing my athritas to get worse and my knees are so painful even after an operation.	76. Depressed 77. Impact on joints
100		
99		
98	I feel if I could lose a little it would improve my mobility by making movement easier	78. Aware of impact on mobility
97	Desperate.....Try and try to lose it	79. desperate
96	I watch what I eat and so weigh myself most days.	80. Control eating 81. Self weigh daily
95		
94	im fine	82. happy
93		
92	In the past few years it is not something I have given a great deal of thought primarily because I have been hospitalised on three or four occasions due to several illnesses	83. Other priorities
91	I am very unhappy about being overweight. I was never overweight when I was a child but it is a family trait on my mother's side although my brother isn't overweight	84. Unhappy 85. Family trait
90	I feel very heavy at present. I keep trying to lose weight because I know I would be more confortable, clothes, less pain. I do not diet now, but try to eat less and watch what I eat, but obviously it is not enough	86. Aware of overweight 87. Aware of impact on pain 88. Try controlling intake 89. Not enough

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
89	Ideally I would like to get down to about 12st but it is difficult because I am limited as wgat I can do because of my arthritis	90. Want to lose 91. Mobility limit (arthritis)
88	I am not concerned with vanity - I was only a size 14 but I knew i had to do something to help myself to stay at a level of mobility that i could cope with. My arms are much weaker and I have a lot of pain. I have already lost 1st4lb and can feel the difference already. I plan to get down to 9st	92. Looks unimportant 93. Aware of impact on mobility - motivator
87	As I dont know what i weight, I am more concerned about my size. I used to have slim hips for my height and bone structure, but have spread since having to sit all the time. Though a well-padded bottom reduces the risk of pressure sores! My trunk has excess fat on it, though my lower arms and hands and my shoulders are quite bony. My legs are permanently swollen as my circulation is poor	94. Concerned about size 95. Impact of limited mobility (sitting)
86	under control	96. controlled
85	Really upset	97. upset

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
84	It has been a problem since a long stay in hospital in my teens. The food was poor, and our parents "topped up" at visiting time. I remember the hospital staff did decide some of us were too heavy, and put us on a diet. I recall "corned tiger" - the name we gave to a thin slice of purplish meat (cheap corned beef probably) with what passed as salad in these days - limp lettuce leaves and tomato. Yuk! That seemed to turn up quite often, probably because it was easy for the kitchen. I hate my weight. It is a constant problem. I almost see food as an enemy - a harmful addiction. You can avoid other substances if addicted, but you have to eat. I feel I either feel hungry and virtuous, or guilty because I have probably eaten a quantity that will put on weight. This has been my life. I have put on some weight recently - I think because increased fatigue has reduced activity, and the 2 recent severe winters left me housebound for weeks and unable to get exercise. Because I am, or should be, on a diet all the time, I have taken a conscious decision not to be a social nuisance (I can't have that, I am on a diet). When with friends I have what they are having, and try to cut back later. I have a sister, and sister-in-law who are on the most peculiar food exclusion diets, and observing the difficulties they cause their families, I vowed not to be the same. (It doesn't seem to do them much good either!) This sounds very neurotic, and so it is. Having been nagged about my weight since being a teenager, and knowing I should keep it down, I just seem to go about feeling guilty about eating, and having an addiction to food.	98. Hate weight 99. Hungry and virtuous or guilty 100. Food as enemy/addiction 101. Aim not to be social nuisance 102. Guilt on eating, nagged since youth 103. Cant avoid eating 104. Reduced activity (fatigue) 105. Bad weather impact 106. Past experience impact
83	Retired due health (mobility) problems age 55 when weight peaked. Knew I was too heavy and consciously increased activity (joined gym/seated gardening) and lifestyle to improve core fitness and reduce weight. Has been stable for 3-4 years and I'm happy with the balance of weight/activity/fitness/lifestyle. Could reduce wine, but I enjoy it and it's not increasing weight! Still attend gym 2x per week, light gardening, diy and outings, eat what I want and social drinking and don't feel I am denying myself - have adjusted and incorporated exercise and diet into lifestyle. Re Q14 - have answered once or twice because, although constantly 'aware', I don't feel I am 'managing' by dieting regimes etc. It's just day to day living now that I achieved the reduction I wanted 5-6 years ago.	107. Aware of impact of OW 108. Happy (with present balance) 109. Increased activity, adapted lifestyle 110. Lifestyle approach
82	Horrid. Hate it! Makes me feel unattractive.	111. Hate it 112. unattractive

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
81	I want to lose weight around my waist.	113. Want to lose
80	hate it	114. Hate it
79		115.
78	I am trying to lose weight and keep weight off my legs I feel it is a losing battle as I cannot get enough exercise. I go swimming twice a week but it doesn't seem to help. If you can come up with something please let me know	116. Losing battle 117. Cant exercise enough
77	Depressed	118. depressed
76	Uncomfortable, consious and very fed up with it - some days to the point of depression.	119. Depressed/Fed up 120. Uncomfortable 121. Conscious
75		
74	Very depressed. Managed to keep my weight under control until I got in my forties. Then had an illness which I now believe was the start of post polio syndrome as I was then unable to keep active (because caused to much pain in joints). I know I must lose weight to help my mobility but because of depression its a vicious circle. I comfort eat!	122. Depressed 123. Aware of impact on mobility 124. Vicious circle (weight/comfort eat) 125. Trigger? - inactivity due to illness
73	I would wish to be up to a stone lighter, and recover some body toning	126. Want to lose
72	uncomfortable	127. Want to lose

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
71	overweight	128. Aware of OW
70		
69	Reasonably happy. It is totally stable and I cannot reduce more however hard I try.	129. Happy 130. Cant reduce more
68	not good	131. Not good
67	I feel that I need to try to be as active as possible within the confines of my wheelchair, as when walking this was very hard work (like a good workout) to walk around. Now of course, i don't get this kind of exercise. However, I also feel my weight gain is part of the ageing process	132. Want to be as active as possible 133. Exercise limited as in wheelchair 134. Weight gain part of normal aging
66	needs to be kept at present level to prevent mobility at joint problems	135. Want to avoid OW, mobility issues
65	not happy with it, losing it is hard	136. Unhappy 137. Hard to lose
64	Quite happy with my weight and I take care not to eat too much. My spinal curvature has got worse over the years which has reduced ny height for 5ft 6inches at my highest.	138. Happy 139. Control eating 140. Assessment issue

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
63	I have been aware of polio and weight all my life. The more weight the harder it is to walk, especially with a calliper which you swing to walk. It puts pressure on you spine and back. Now I have to leg supports, it is even harder. I don't worry about weight from the point of view of looks. It is more that I love to get out and about and walk. I love the countryside. I used to swim, especially the crawl. If I was careful, I used to be able to walk without callipers to the pool. I just locked my left knee back and did not need support on my right. I damaged my shoulder so I can not do the crawl. I would dislocate my shoulder. I really require a hoist for safety. My mother always warned me about the dangers of breaking my left leg due to bad circulation. It would take a long time to heal and resting up my muscles would dystrophy. Since being back in the UK, I find it harder to control eating and weight control, plus the lack of exercise. I also do not have the medical support and encouragement. In Australia, the climate helps you to not eat so much and what you do eat is a lot more salads. I miss my swimming and exercise. I felt fitter and more in tune both in muscle & lung strength.	141. Aware of impact on mobility (polio) 142. Looks unimportant 143. Aware of impact on getting out (to countryside) 144. Impact of injury on exercise (swimming) 145. Impact of weather on exercise ability 146. Medical support lacking in UK cf AUS
62	could do with losing 2-3 stone but can't exercise and am only eating 2000-2500 cals/day not much I can do about it	147. Misconception on calorie requirements
61	I am constantly aware of being overweight as I feel this contributes to limiting my mobility and increases the pain in my arms as I have to walk with a stick, haul myself up steps and out of chairs etc. I felt much better about myself when my weight was reduced by swiming, but without exercise my weight balances ar 12st	148. Want to lose 149. Aware of impact on mobility/pain 150. Inability to exercise (swim - what stops?)
60	Too heavy, wish I was a stone lighter	151. Too heavy
59	usually hovers around 8.5st so I don't monitor it	152. OK
58		

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
57	Maybe a couple of Kg overweight I have put on a lot of muscle due to my high swimming activity	153. Slightly OW 154. Swimming - increased muscle
56		
55		
54	bloody awfull.	155. awful
53	OK	156. OK
52		
51		
50	I need to lose weight because i think it would improve my mobility	157. Want to lose 158. Impact on mobility
49	too heavy by at least 10lbs	159. Too heavy
48		
47		
46	It is OK but if I'm honest I could do with being half a stone lighter.	160. OK 161. Could be bit lighter
45		

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
44	I am very careful to keep a control on my weight so as not to overburden my legs. I feel that 50 kg is about the right weight for my height and if I go over that I cut down on my food intake until my weight is 50 kg again. I have no more than 28 g of cereal in the morning or one boiled egg, Only one slice of home made bread with a little cheese or spred for lunch and a piece of fruit and I rarely have a pudding in the evening with my main meal. If I do it will be a small portion of Greek youghurt with a small spoonful of jam or honey or stewed fruit.	162. Keep careful control 163. Aware of impact on mobility (motivator) 164. Very controlled intake
43	Too high and needs to be much lower again	165. Too heavy
42	I feel comfortable with my weight, but would like to lose 4 or 5 pounds to take some weight off my legs. However, whenever I have tried to achieve some weight loss I seem to become slightly unwell so I don't bother anymore. I carefully maintain my present weight by, I hope, a sensible diet.	166. Comfortable 167. Would like to lose some 168. Aware of impact on mobility (motivator) 169. Feel unwell when trying to lose 170. Maintain by healthy eating
41	If I am too heavy this affects my mobiity	171. Aware of impact on mobility
40	I bothers me, because breathing is harder and i feel uncomfortable.	172. Bothered 173. Harder to breathe (if OW) 174. Feel uncomfortable (if OW)
39	I try to keep it down by swimming two hours a week and eat regularly. If I overeat at a restaurant, I cut down the next day.	175. Try to control 176. Exercise (swimming) 177. Control intake
38	I know it is because I can't move about or exercise as I don't have the strength. If I do try to do something I end up worse off.	178. Difficulty exercising (strength) 179. If try, end up worse off

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
37	I have had a constant battle as you can see from age 25 when I weighed over 17 stone, I constantly watch, but since the death of my husband 8 years ago and since being in the wheelchair i have found it hard to keep a healthy weight. I have resisted an electric wheelchair so I can at least self propel although this is against my GP wishes. My weight does fluctuate and in winter does go up. I am constantly freezing cold even with central heating and eat more. At the moment I am eating very healthily and am losing weight slow but sure. I come from an overwieght family - three brothers and a sister all obese so i pride myself in keeping most of the weight off. I eat very little and have a treat of a decent meal once a week. However it is worth it because I do feel very healthy, I don't suffer coughs, colds or anything like that and could quote the fat content and calorific value of most things. As I'm now on my own I only buy low fat food I can eat and only eat chicken or fish, no cheese ,butter, marg, cakes biscuits, nothing . Wholemeal bread, pitta , no chips [exept for a treat lots and lots of fruit and veg and skimmed milk - I should be like twiggy !!! I eat three meals a day and no snacks, drink loads of water so what more can I do !!!	180. Battle 181. Effort to control worth it 182. trigger - loss of spouse 183. trigger - in wheelchair 184. use self propel WC to keep activity up (against GP advice) 185. eat healthily, control intake 186. overweight family bg
36	Most unhappy as it has a direct effect on my mobility.	187. Unhappy 188. Aware of impact on mobility
35	I know it is stopping me enjoy life to the full. I would like to be able to walk moreand/ or cycle which would help, I'm sure, but cannot due to the pain and exhaustion caused.	189. Bad impact on lifestyle 190. Impact of pain/fatigue
34		
33	I have accepted the fact that I hover around the 14.5 stone region. I would like to be thinner but I don't worry about weight issues - except when buying clothes!!!! But that's more of a woman thing.	191. Accepted OW 192. Only worry when buying clothes 193. Woman thing
32		
31		

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
30	There is little that I am able to do about it	194. Little I can do
29		
28		
27	Fine	195. happy
26	Frustrated!! No matter how little I eat I do not seem to be able to loose any weight in-fact as time goes by I just seem to put on more and more weight. I do realize that the problem is lack of mobility and I should eat less and less but hey...you only have one life, and it's short!	196. Frustrated 197. Inability to lose, even when eating little 198. Mobility is problem 199. Should eat less 200. Impact on life quality of eating less
25	Too high	201. Too high
24	unable to exercise and enjoy food	202. Unable to exercise 203. Unable to enjoy food
23	very sad and miserable especially in hot weather	204. Miserable 205. Worse in hot weather
22	uncomfortable	206. uncomfortable
21	I am far too heavy but can't shift it.	207. Too heavy 208. Unable to lose
20		
19		

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
18	Im still a stone over weight and find I have to live on 900 calories per day to stay stable, if I go over that I gain weight, I feel I just look at food and the weight goes on, I have been on a diet for 22 years and find it most annoying	209. Too heavy 210. 900 cals to stay stable 211. Annoying to diet for 22yrs
17	Hate it! It's restrictive as it slows me down; I can't see my feet and I feel miserable as, short of starvation, it won't budge.	212. Hate it 213. Impact on mobility 214. Cant see feet 215. Cant lose unless starve
16		
15	Frustrated - it is such a struggle to maintain a healthy weight especially as I cannot do a lot of physical exercise. I am embarrassed about the shape of my body due to my weight and wish that there was more support for disabled people to participate in specially constructed exercise plans which take the individuals physical capabilities into account.	216. Frustrated 217. Struggle 218. Cant exercise 219. Embarrassed 220. Want more support for disabled to exercise
14	Do not like being the weight i am Have very short below the knee limbs I am never sure if the medical or mental health problems are behind my inability to lose weight	221. unhappy 222. Commplication with co-morbidity
13	Demoralised. Have had problems with my weight since early 30s. Lost over 2 stone twice but put it back on again. From being an underweight teenager I became an overweight adult. I think food became a comfort for me. Women seem to overeat for various reasons. With me, I did it mainly because living with a deformed body is hard. (Polio left me with a curved spine and restricted my growth). On a pleasanter note, I learnt to cook! Reasonably good at it and I find great pleasure in eating out too. I am far too heavy for my height. The fat is basically around my trunk. Getting clothes to fit is now very difficult. You must be thinking, "Why the hell doesn't she lose the weight?" Certainly being more mobile would have helped but another reason for me is 10stone or 7 stone, I'm still deformed. It gets my husband down. He is constantly asking me to lose weight as he's fearful for my health.	223. Far too heavy 224. Demoralized 225. Food as comfort (women?) 226. Food as leisure activity (eating out) 227. Body image impact deformed even if lose 228. Learned to cook 229. Effect on partner

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
12		
11		
10	My weight is the bane of my life. It's a constant struggle. I alternate between being on a very restricted regime and being more relaxed about my weight. Having a wide circle of friends, eating out is what I DO and although I know I should have the salad and the fish, I don't always feel like having the salad and the fish. I realise I'll never be 8 stone, or even 10 stone. I'd be happy to be 12 stone and a size 16. When I got down to 9stone 9lbs in my early twenties I was a size 14 and was still in a size 38 bra. I have a huge ribcage and my upper body developed to compensate for my weak legs. I know I would look ridiculous below 10 stone - therefore I am being realistic in my weight loss goals. I know EXACTLY what I have to do to lose weight - but it's not much fun. I have to be completely obsessed to lose weight. As my exercise tolerance is drastically reduced it's virtually impossible for me to use up the calories I consume - even on a healthy low fat diet. I have researched bariatric surgery (gastric banding) but of course I'm not within the NHS criteria (BMI 43)and don't see why I should pay £7,000 for surgery which other people get free for basically eating themselves into oblivion. So far I've managed to avoid diabetes and high blood pressure but there's a family history of heart disease. Plus if I go off my legs and use wheels full time I'll probably just get bigger. So that's how I feel about my weight.	230. Bane of life 231. Alternated restriction and relaxing 232. Eating part of social life 233. Body image, would look unbalanced lighter (large upper body) 234. Identity 235. Cant exercise 236. Want surgery - don't meet criteria 237. Not much fun (to reduce intake) 238. Confusing image vs health reasons for losing

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
9	i do feel suicidal about it at times - I eat low fat organic food and think about everything that i eat- I had a perforated colon 4yrs ago and have a stoma, well managed, but i seem to be one mass of scars and hacked up body -having had polio has always left me feeling clumsy, muscles burn and don't work, would be easy to give up and think of it every day, but have good family and friends and interests - distract myself and do not discuss my deeper feelings, for the moment, just get on with it - my latest efforts as i have a liitle/big voice in my head all the time that says, must try harder, do more - everyone seems to think it's my/our fault if i/we don't exercise in a convential way - is to ask my gp for a gym referral, he laughed and wrote it for me on prescription, i await to hear there is considerable dissonance between my feelings and what i hear from people - i wear makeup, good interesting clothes and jewelry, some think i'm lovely, beautiful, funny, clever and have a spirited personal and political identity but losing weight is like a vertical mountain that i cannot conquer, it just doesn't shift i don't believe in diets, just good eating habits, enjoying food and company, occasional glass of wine, but as it gets more difficult and painful to move around, my frustration and depression increases as if i'm being smothered i fantasise that if i was lighter i would be a free spirit, so there's no telling that being thinner might confirm even worst fears! i don't hate myself, in fact i feel very, very sad for myself - i hate polio and the feeling that i am shackled to it ,and its embodied in my weight, which is the way it is because i can't run up mountains my husband adores me physically and in every other way - he thinks we should accept things as they are and not waste energy on rage well, i still rage	239. Frustrated 240. Depressed 241. Hate polio - shackled 242. Weight as symbol of polio 243. Suicidal 244. Mountain cant conquer 245. Low fat diet, control intake 246. Use distraction 247. Don't discuss deeper feelings 248. Internal voice say must do more 249. Image wrt other people's 250. Enjoy social aspects of eating 251. Impact of mobility, pain 252. Spousal support 253. Feel others blame (us) if don't exercise conventionally
8	I feel very uncomfortable because it seems to affect my walking & without being able to walk very far I feel I am not getting enough excercise which is keeping my weight high.	254. Uncomfortable 255. Aware of impact on mobility 256. Unable to exercise

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
7	I lost a lot of weight 15 years ago (deliberately) and felt a lot better physically mentally and emotionally. I've remained at broadly the same weight ever since but notice I am starting to put a bit back on which I feel quite upset about. On the other hand I feel quite confident I can stop the gain and lose the few pounds by being a bit more aware of the changes I need to make to allow for my lower activity levels. I do find it a bit challenging though to no longer have enjoyable physical activity as a distraction from eating, and to be sitting around with the possibility of eating for reasons other than hunger! My present weight is actually probably fine for my height, it's really the likelihood of it creeping up that disturbs me. I do feel more attractive at a lower weight, as well as knowing it puts less strain on my joints.	257. Happy 258. Can control weight gains 259. Aware of adaptation needed for lower activity 260. Cant use exercise (anymore) as distraction from eating 261. Boredom eating 262. Want to avoid OW 263. Feel more attractive lighter (motivator) 264. Feel less strain ligther (motivator)
6		
5	I AM DESPERATE TO LOSE WEIGHT PRBLEMS WITH BREATHING AND MOBILITY PARTICULARLY LIFTING MYSELF FROM SEATED POSITION	265. Desperate 266. Impact on breathing and mobility
4	I need to lose 7lbs	267. Want to lose
3	Although I have not put on many pounds I have a lot more fat, especially round my waist and hips. As my muscles weaken I think they must be turning to fat. The only way to keep control is to be careful of what I eat. Any fat that goes on will not come off again as I cannot exercise. I shout at the TV when yet again I am told I must exercise. I would love to go for long brisks walks or to go swimming again but I am not able to now. I know I would not have this extra fat if I could be more active. I try to control my weight as I cannot carry shopping so I cannot afford to give my back and legs the equivalent of extra shopping to carry every day! On the other hand I think it is more important that I am healthy rather than thin, so I will not starve my body of the nutrients it needs. I eat good nourishing food and no junk food.	268. Feel muscles turning to fat 269. Control intake 270. Cant exercise 271. Upset by media environment - told must exercise 272. Want to avoid nutritional deficiency 273. Eat healthily

SM NO	How do you feel about your weight? Feelings on weight difficulties success/failure aids approach	Codes In vivo?
2	Frustrated by an apparent inability to shift it. Monitoring calories is a pain but the only way I can even keep static nowadays.	274. Frustrated 275. Monitor intake
1	Would like to be half a stone lighter.Have suffered with anorexia in my teens.	276. Would like to lose 277. Past anorexia

Appendix 8. Example section of Excel Spreadsheet

The excel spreadsheet used to code the qualitative data is too large to printout here. An example of the top level sheet is given to illustrate what the downloaded data looked like and how some of the coding was carried out.

The following pages show the top 25 rows of the excel spreadsheet. The first five pages contain the columns of data as downloaded from Survey Monkey, the last three show the columns containing some example of coding of sub-themes for each respondent against topics and themes in the column headings to enable data analysis. This also shows how numerical scores were assigned for polio disability, mobility, walking ability and activity.

CHECK												How did polio affect you physically?			How mobile are you?	
SM N:O	RespondentID	CollectorID	StartDate	EndDate	IP Address	Em:	Firs	La	Cu	1. At what age polio?	2. What age now?	3. Arms	Legs	Trunk	4. How I get about	5. If you are able to walk, with or without aids, how far can you walk?
	Record Number															
141	1971914902	27484614	08/29/2012	08/29/2012	86.150.236.82					4	64	Nothing diagnosed	Extensively	Slightly	Self-propelled wheelchair	Around the house
140	1971902157	27484614	08/29/2012	08/29/2012	86.150.236.82					7	70	Moderately	Extensively	Extensively	motorised wheelchair	10-15 mins close to home
139	1952925062	26109602	08/17/2012	08/17/2012						3	61	Slightly	Extensively	Moderately	walk without aids	15-90 mins round shops or garden area
138	1940845468	27484614	08/07/2012	08/07/2012	86.148.218.169					1	59	Extensively	Moderately	Slightly	walk with walking sticks or wheeled frame/rollator	Around the house
137	1940835833	27484614	08/07/2012	08/07/2012	86.148.218.169					3	65	Moderately	Moderately	Nothing diagnosed	walk without aids	longer
136	1940823499	27484614	08/07/2012	08/07/2012	86.148.218.169					1	63	Nothing diagnosed	Extensively	Slightly	walk with walking sticks or wheeled frame/rollator	10-15 mins close to home
135	1940814257	27484614	08/07/2012	08/07/2012	86.148.218.169					7	68		Moderately		walk with walking sticks or wheeled frame/rollator	10-15 mins close to home
134	1940805881	27484614	08/07/2012	08/07/2012	86.148.218.169					2	60	Moderately	Extensively	Slightly	motorised wheelchair	Around the house
133	1940789536	27484614	08/07/2012	08/07/2012	86.148.218.169					1	66	Moderately	Moderately	Moderately	walk with walking sticks or wheeled frame/rollator	10-15 mins close to home
132	1940623005	27484614	08/07/2012	08/07/2012	86.148.218.169					4	75		Extensively		walk with walking sticks or wheeled frame/rollator	10-15 mins close to home
131	1940615722	27484614	08/07/2012	08/07/2012	86.148.218.169					7	66		Extensively		walk with walking sticks or wheeled frame/rollator	10-15 mins close to home
130	1940609170	27484614	08/07/2012	08/07/2012	86.148.218.169					4	74	Nothing diagnosed	Extensively	Nothing diagnosed	Self-propelled wheelchair	Around the house
129	1940604737	27484614	08/07/2012	08/07/2012	86.148.218.169					1	87		Moderately		motorised wheelchair	Around the house
128	1940597237	27484614	08/07/2012	08/07/2012	86.148.218.169					19	74	Moderately	Extensively	Extensively	Self-propelled wheelchair	
127	1940585029	27484614	08/07/2012	08/07/2012	86.148.218.169					1	59		Extensively	Extensively	walk with walking sticks or wheeled frame/rollator	10-15 mins close to home
126	1940580129	27484614	08/07/2012	08/07/2012	86.148.218.169					9	70	Extensively			walk without aids	longer
125	1939916872	27484614	08/06/2012	08/06/2012	86.148.218.169					3	65		Moderately	Moderately	walk with walking sticks or wheeled frame/rollator	15-90 mins round shops or garden area
124	1939909869	27484614	08/06/2012	08/06/2012	86.148.218.169					3	68			Slightly	walk without aids	longer
123	1939901518	27484614	08/06/2012	08/06/2012	86.148.218.169					2	64		Extensively		walk with walking sticks or wheeled frame/rollator	10-15 mins close to home
122	1934200406	26109602	08/01/2012	08/01/2012						3	58	Slightly	Moderately	Nothing diagnosed	walk with walking sticks or wheeled frame/rollator	Around the house
121	1930841165	26109602	07/29/2012	07/29/2012						1	65	Slightly	Extensively	Slightly	Self-propelled wheelchair	Around the house
120	1923751301	26109602	07/23/2012	07/23/2012						3	66	Moderately	Moderately	Moderately	walk with walking sticks or wheeled frame/rollator	Around the house

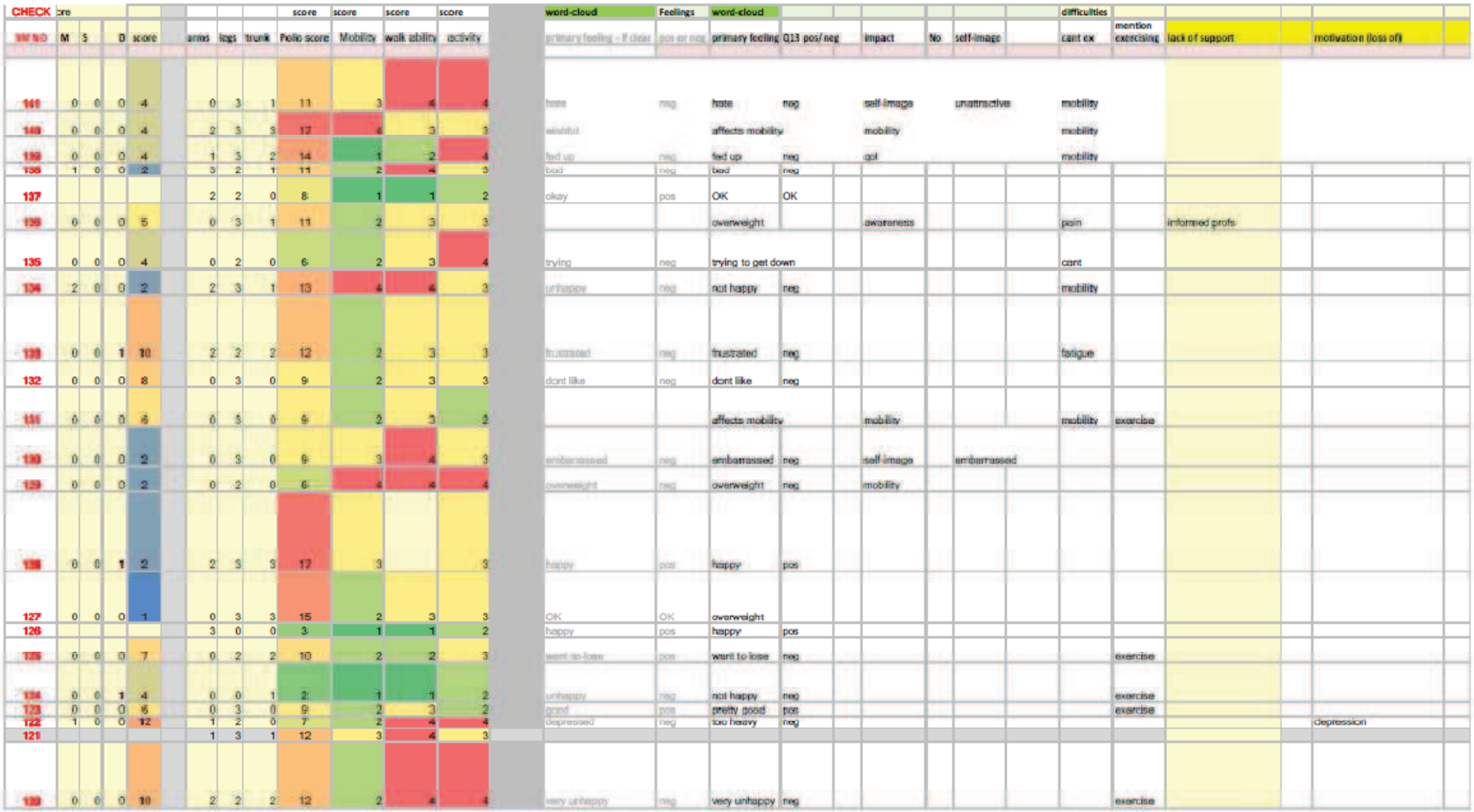
CHECK						
SM N O	6. Has your mobility changed ?	7. If yes, please describe roughly how and when.	8. your present activity level?	9. your present state of health?	Q10. other medical conditions?	Other (please specify, or list all if more than one)
141	Yes	Until the age of 60, I walked with full calliper on left leg and boots and was able to walk easily 100yds without a problem. Now I have to walk with 2 sticks in the house and use a wheelchair outside so the last 4 years has seen a marked deterioration	Sedentary	poor	high blood pressure	
140	Yes	increasing muscle weakness has severely affected my mobility. Also repetitive strain problems with my arms and wrists through more pressure put on crutches. I have been diagnosed with post-polio syndrome	Low activity	fair	high blood pressure	decreasing mobility and muscular fatigue preventing exercise
139	Yes	Gradually worsened over the last 10 years and now diagnosed with Post Polio Syndrome.	Sedentary	poor	No	Arthritis in neck, and knees. nerve pain in nec
138	Yes	about 12yrs ago, falling more and getting weaker	Low activity	fair	No	
137	Yes	father constantly walked with subject as a child to strengthen legs with success	Medium activity	fair	No	
136	Yes	In the mid 80's I noticed I was falling down a lot due to my polio leg giving way and was given the option of fused knee or calliper. I choose leg calliper and that is what I wear now. Left side good leg is now causing me a lot of problems (PPS)	Low activity	fair	No	
135	Yes	severe pain in heel - 1975 (surgery) " " - 2002 (surgery)	Sedentary	fair	high blood pressure	
134	Yes	My mobility has got much worse in the last 5 years as I can no longer walk, even with the aid of calipers and crutches, for more than a few steps	Low activity	fair	type II diabetes	
133	Yes	Increased weakness, mobility much worse, painful muscles, from age of 55 when diagnosed with PPS	Low activity	fair	high blood pressure	poly arthritis, neck, shoulder, arms, knees
132	No		Low activity	fair	high blood pressure type II diabetes	high BP T2D
131	Yes	My mobility started to change about 10yrs ago when I realised I couldn't walk as far & has gradually decreased to now where I need support of a walking frame - can't manage with sticks - I have an electric scooter for longer distances but am OK on the flat where I live	Medium activity	fair	high blood pressure	epilepsy - but don't know if it affects my weigh
130	Yes	During my 40s I seemed to be unable to get my legs to coordinate after a few steps & this affected my balance greatly & left me unable to stand without a stick	Low activity	fair	high blood pressure high cholesterol type II diabetes	high BP high Cholesterol t2D psoriasis bo
129	No		Sedentary	poor	high blood pressure high cholesterol	high BP high Cholesterol
128	Yes	I used to walk with elbow crutches, callipers and a back support but nearly twenty years ago had a extremely bad fall when I nearly broke my neck and became dependant on my husband for about six weeks. Walking had been a bit like being on a tightrope & I had 'got away with it' (ie not injured myself so badly) for over 30 years, so decided to give up	Low activity	good	No	
127	Yes	Due to PPS now suffer xxxx? fatigue + stress on spine which is curved due to polio complications	Low activity	poor	high blood pressure high cholesterol	high BP high cholesterol, both controlled thr
126	No		Medium activity	good	No	
125	Yes	I cannot walk without a walking stick. My legs ache a lot more, bending etc are very painful. I had polio in 1950 when I was years old	Low activity	fair	high blood pressure high cholesterol	high BP high cholesterol
124	No		Medium activity	good	high blood pressure high cholesterol	high BP high cholesterol
123	No		Medium activity	fair	high cholesterol	
122	Yes	neuropathy in legs and feet also hands swallowingprobs bowel and bladder probs balance not good	Sedentary	poor	other	heart attack,heart failure,atrial fibrillation,dive
121	Yes	cont walk with crutches like I did and suffer whit asthma	Low activity	fair	No	
120	Yes	I managed to lead a fairly active live with assistance until about 15 years ago when I started to trip and fall more regularly. Since that time I have suffered from muscle weakness. I now have lost a lot of convidence when walking.	Sedentary	fair	high cholesterol	My cholesterol was found to be a little high la

CHECK	What are your body measurements?				How has your weight varied during your life?				
Int No	11. Height	Waist circu	Hip circu	Present weight	12. What is the lightest weight ?	What is the heaviest weight	Q13. How do you feel about your weight?	14. Have you ever tried to lose weight?	15. experienced difficulty in healthy weight?
141	5ft2.5	41in	44in	13st7	8st10 age 36	13st7 age 64	I hate being so overweight as none of my clothes fit properly and don't feel attractive. I also get very frustrated when I read artides in women's magazineswhich tell me that if I want to lose weight I have to do more physical activity then give suggestions such as walking the stairs instead of using the lift none of which I can do.	2-5 times	yes
140	4ft10 sever	33in	36in	8st	7st in 20s	9st in 60s	would like to keep weight under control as the heavier I get it is more of a strain on my weakening muscles, and then I become more immobile	once or twice	yes
139	5' 3.5"	34"	34	11st 1.5lbs	20 yrs....7.5st	61 yrs.....11.5 st	Fed up	constantly try to manage weight	yes
138	5ft5 (sinal	28in	40in	12st11	9st8 40	16st 57	bad	constantly try to manage weight	yes
137	5ft6	22in	30in	8st	7st12	8st8	okay	never	yes
136	5ft1/2in (sh	37in	44in	12st7	8st	12st7 age 63	I have tried diets but I like my home cooked food too much, and how can I exercise when I get a lot of leg pain. I know I am a few stone over weight, but I am light compared to some people	2-5 times	yes
135	5ft9	48in	42in	19st4	11st7 (21yos)	19st8 (68yos)	trying to get it down	once or twice	yes
134	4ft11	50in	53in	95kg	8st approx 21yrs	95kg 55 years	not happy at all because of my inability to actually lose any weight	more than 5 times	yes
133	5ft6	50in	58in	18st6	11st7 20-40yrs	19st3 55plus	unhappy, frustrated I know I'm too heavy, I have always been aware of eating healthily and only have breakfast and evening meal and have done for some years now but fail to lose weight	constantly try to manage weight	yes
132	6ft	48in	46in	19st8	10st4 at 25	19st8 75	I don't like it but its hard to lose	constantly try to manage weight	no
131	5ft4	32in	39in	10st8	8st in twenties	10st6 now (66)	Would like to lose about a stone as I have arthritis in my left leg (good leg) & I find it easier to keep mobile the ligher I am	constantly try to manage weight	no
130	5ft2	45in	52in	very overweith, not able to stand on scales			I feel very embarassed & unhappy about my weight even though I realise I could be more in control over my diet I obviously comfort eat so only have myself to blame	once or twice	yes
129	blank				9.5st at 30+	13.5 st - 70+	I feel overweight at 12 stone and feel it would be easier to get around if I was slimmer!	once or twice	yes
128	5ft6	28in over b	36in ove	9st	8st, 19 after polio and	10st 37-40 after birth of	happy. I am concerned, not that I am overweight now, but that I do not want to become overweight	constantly try to manage weight	no
127	5ft7 spinal	38in	36in	13.5st	11.5st 25-38	13.5st 40 in	I feel that I am on the 'overweight' side but not greatly as I signed? some of it as a natural consequence of middle age spread	once or twice	no
126	5ft3	35in	38in	9st app	no significant differen	no significant differenc	happy	never	no
125	4ft8 slight	size 18 in t	see abov	12st	10st app	14st app	I wish i could lose weight I eat a healthy diet	constantly try to manage weight	yes
124	5ft 1/2in	38in	44in	11st	8.5st age 35	11st at present age	not really happy, it is a bit harder to lose when one gets a bit older. That is why I walk as much as possible dont really diet, just cut down on foods etc	once or twice	no
123	5ft9	32		9.5st	9st at 62	9.5st	pretty good	never	no
122	5ft 9ins	45ins	40ins	17st 1lb	10st 5lb at15	17st 9lb	to heavy	constantly try to manage weight	yes
121									
120	5ft 1in	37ins	48ins	12st 7lbs	9st 10lbs at 28	13st 1lb at 62	Very unhappy.	constantly try to manage weight	yes

CHECK		If you have tried approaches to lose weight, prevent weight gain or maintain a healthy weight, what methods have you used?								
IM_NO	Q16. If so, what difficulties did you experience?	17.Nutritional assessm	Self-chosen diet	Physiotherapist assessment ar	Exercise classes	Self-directed exercise	Medications	Surgery	Other (please specify)	Q18. did any work
141	My ability to exercise has markedly decreased in the last 4 years but my appetite has stayed the same which creates problems. I am also permanently on steroids because of two eye conditions called uveites (?) and optics neuritis and that has not helped		used a few times	used once		used once				yes
140	unable to do exercises	used a few times	used a few times							No
139	I enjoy a social drink and meals out with friends and I cannot use the exercise bike or walk far.		used a few times	used a few times						yes
136	yo-yo can't keep weight stable					used once	used once			No
137	often disinterested in food chaotic approach to eating									No
136	not being able to exercise		used many times			used a few times				No
135	lack of ability to exercise		used a few times			used a few times				No
134	because of my inability to do any effective exercise to lose any weight being mainly confined to an electric wheelchair						used a few times			No
133	1) find myself getting very tired much quicker 2) experience low sugar symptoms during spells of activity - housework, shopping, etc 3) get annoyed with yself & give in to temptation too quickly	used many times	used many times		used many times				presently trying a 'healthy lifestyle plan' as opposed to 'dieting'. Have decided to use a different approach	
132	blank	used a few times	used once	used a few times	used a few times	used once				No
131	Although this is the heaviest I have been I think a lot is because of my age & not being as mobile because of this I try to eat sensibly instead of yo-yo dieting		used many times		used many times					yes
130	lack of will power is the only explanation		used a few times							No
129	Not being mobile, I spend more time sitting watching TV playing board games and cards and of course eating!		used a few times							No
128	asserting and maintaining the necessary self-discipline		used once						no tick above. I do not use a diet, just a motto: EAT LESS. I was once told 'if you eat less your body adapts and then wants less' and it have found this to be true. I expect the back support helps! (its very tight)	yes
127	never felt 'really overweight'		used once							yes
126	blank									yes
125	being so short I seem to put weight on easily	used once	used a few times		used a few times	used a few times				yes
124	blank					used many times			dont really diet, just cut down on foods etc	No
123	blank	used many times				used many times				yes
122	felt depressed	used many times	used a few times	used a few times	used a few times	used a few times	used once			yes
121										
120	During periods of inactivelty following operations or accidents e.g. broken knee.		used many times	used a few times	used a few times	used many times				No

CHECK	any methods worked ?		
	Q18. If yes, which ones worked	Q19. What aspect of these methods made them successful or unsuccessful for you? Success/failure	Q20. Please add any additional comments you feel are relevant
141	In the days before I became unable to exercise a combination of smaller portions plus more swimming usually helped me to maintain a healthy weight	What helped me most was firstly that I felt in control and secondly that I was able to fit what I needed into my daily routine	
140		limited as to what exercise I can manage	my weight doesn't vary. A slow increase as I've got older, co-inciding with muscle weakness
139	When my wife was slimming we did it together using Slimming World.		
138	not in the long term	blank	
137	no tick blank	blank	I am obviously approaching the weight issue from the other end, not the one that you are most concerned with!
136		blank	not enough people in the physio depts are aware of what polio people can't do in regards exercise
135		1/ prescribed diet: don't like most of the food recommended 2/ prescribed exercise: not been told of any available 3/ exercise classes: would have to be for the disabled 4/ medications: waiting for the 'FAT' pill 5/ surgery: would be a choice if I could afford it	given this by a member of the Manchester Polio Group
134		after a period on medication I did not feel they were working at all, also they caused problems	
133	no tick above am hopeful the present plan will work	I think I've decided I get a psychological block followwing 'diets' and do not like attending classes. I had a hip replacement 18 months ago and am conscious of not needing any more surgery so want to maintain my joints and well-being	Exhaustion is a common problem to people with PPS. Managing it in regard to diet means I need to have carbs and protein for breakfast to enable me so do the main activity of the day, eg shopping, housework, etc in a morning. By the afternoon I am then only able to do sitting jobs or activities that don't require much energy. Evening activities are practically non-existent now as I am too tired
132		blank	
131	mainly both	Go to Pilates class every week which I find beneficial although I cannot do all the exercises. I find it keeps me supple & have noticed a difference when not going for a few weeks - example - illness or holiday. I also try to eat as much fruit and veg as I can although I lose my way sometimes	
130		I can only blame lack of willpower	
129	no tick, blank	blank	
128	the other	blank	My method had to be introduced and extended gradually(underlined) but worked well so far.
127	not yes but no tick above on self chosen diet (soups etc) I did lose some weight (so can do again - if choose)	I can only control my weight by dietary methods as I cannot exercise. I do believe in the ditty 'the human body - is mainly torso' the more you eat - it is more so! so eating less has been effective for me - on the occasion used	I've always seemed to maintain a steady weight. From 20s to 40s about 11.5 stone and from mid 40s on about 13.5 stone on average with small variables either way. I think I look more portly than I 'really' am due to scoliosis - poor posture as? my right hand side stomach muscles being weakend by polio
126	not yes but blank	blank	blank
125	weight watchers	being weighed every week	I am very lucky I can walk around (very slowly) But I try to go out each day - but I have rest afterward thank you for trying to help us god bless
124		blank	
123	both as mentioned	physical exercise daily and keeping active	
122	self chosen diet	dont know	
121			
120		Weight watchers is the only method that has worked for me in the past but at present not very successfully. I think the main reason is lack of exercise and body has got used to the diet. The excerise class that the physio's sent me to does help me, but find it very hard sometimes and takes me a couple of days to recover from it each time I go. My muscle weakness and balance problems are a real hinderence.	

CHECK	contacted	removed for confidentiality				CHECK																		methods sc				
SM IVD	Response	Name	tel	email (if available)	address	SM IVD	limited respo	limited web	age	lightest	min BMI	max BMI	BMI now	waist, in	waist cm	Waist, cm	Hip, cm	WHR	M/F	fem waist	male waist	WM group	yr of polio	ea	SCD	PA	EC	SDE
141	yes					141		0	36	55.5	22	34	34	41	104.14	104.14	111.76	0.93	f	104.14		WG2	1952	0	2	1	0	1
140	yes					140		0	25	44.5	21	26	23	33	83.82	83.82	91.44	0.92	f	83.82		AWM (HW)	1949	2	2	0	0	0
139						139		0	20	47.7	18	28	27	34	86.36	86.36	86.36	1.00				WG1	1954	0	2	2	0	0
138	yes					138		0	40	60.0	22	37	30	28	71.12	71.12	101.6	0.70	f	71.12		AWM (OW)	1954	0	0	0	0	1
137	yes					137		0		50.0	18	19	18	22	55.88	55.88	76.2	0.73	f	55.88		LWM (UW)	1950					
136						136		0		50.9	22	23	34	37	93.98	93.98	111.76	0.84				WG2	1950	0	3	0	0	2
135	no					135		0	21	73.2	24	41	40	48	121.92	121.92	106.68	1.14				WG4	1951	0	2	0	0	2
134	yes					134		0	21	50.9	23	42	42	50	127	127	134.62	0.94	f	127.00		WG4	1954	0	0	0	0	0
133	yes					133		0	20-40	73.2	26	44	42	50	127	127	147.32	0.86	f	127.00		WG4	1947	3	3	0	3	0
132	yes					132		0	25	65.5	20	37	37	48	121.92	121.92	116.84	1.04	m		121.92	WG3	1941	2	1	2	2	1
131	yes					131		0	25	50.9	19	25	25	32	81.28	81.28	99.06	0.82	f	81.28		LWM	1953	0	3	0	3	0
130	yes					130		0						45	114.3	114.3	132.08	0.87	f	114.30			1942	0	2	0	0	0
129	no					129		0	30	60.5									m				1926	0	2	0	0	0
128	yes					128		0	19	50.9	18.1	22.6	20.4						f			LWM	1957	0	1	0	0	0
127	no					127		0	25-38	73.2	25	30	30	38	96.52	96.52	91.44	1.06				WG1	1954	0	1	0	0	0
126	no					126		0		57.3	22	22	22	35	88.9	88.9	96.52	0.92				LWM	1951					
125	yes					125		0		63.6	31	44	46						f			AWM (OB2)	1950	1	2	0	2	2
124	no					124		0	35	54.1	23	30	30	38	96.52	96.52	111.76	0.86				WG1	1947	0	0	0	0	3
123	yes					123		0	62	57.3	19	20	20			81.28			m		81.28	LWM	1950	3	0	0	0	3
122	yes					122		0	15	65.9	21	37	35	45	114.3	114.3	101.6	1.13	m		114.30	WG2	1947	3	2	2	2	2
121						121	1	1															1948					
120	yes					120		0	28	61.8	26	35	33	37	93.98	93.98	121.92	0.77	f	93.98		WG1	1949	0	3	2	2	3



CHECK	ore							score	score	score	score		word-cloud	Feelings	word-cloud							difficulties				
IW No	M	S	D	score		arms	legs	trunk	Polio score	Mobility	walk ability	activity		primary feeling - if clear	pos or neg	primary feeling	Q13 pos/ neg		impact	No	self-image		cant ex	mention exercising	lack of support		motivation (loss of)
141	0	0	0	4		0	3	1	11	3	4	4		hate	neg	hate	neg		self-image		unattractive		mobility				
140	0	0	0	4		2	3	3	17	4	3	3		wishful		affects mobility			mobility				mobility				
139	0	0	0	4		1	3	2	14	1	2	4		fed up	neg	fed up	neg		qol				mobility				
138	1	0	0	2		3	2	1	11	2	4	3		bad	neg	bad	neg										
137						2	2	0	8	1	1	2		okay	pos	OK	OK										
136	0	0	0	5		0	3	1	11	2	3	3				overweight			awareness				pain		informed profs		
135	0	0	0	4		0	2	0	6	2	3	4		trying	neg	trying to get down							cant				
134	2	0	0	2		2	3	1	13	4	4	3		unhappy	neg	not happy	neg						mobility				
133	0	0	1	10		2	2	2	12	2	3	3		frustrated	neg	frustrated	neg						fatigue				
132	0	0	0	8		0	3	0	9	2	3	3		dont like	neg	dont like	neg										
131	0	0	0	6		0	3	0	9	2	3	2				affects mobility			mobility				mobility	exercise			
130	0	0	0	2		0	3	0	9	3	4	3		embarrassed	neg	embarrassed	neg		self-image		embarrassed						
129	0	0	0	2		0	2	0	6	4	4	4		overweight	neg	overweight	neg		mobility								
128	0	0	1	2		2	3	3	17	3		3		happy	pos	happy	pos										
127	0	0	0	1		0	3	3	15	2	3	3		OK	OK	overweight											
126						3	0	0	3	1	1	2		happy	pos	happy	pos										
125	0	0	0	7		0	2	2	10	2	2	3		want to lose	pos	want to lose	neg							exercise			
124	0	0	1	4		0	0	1	2	1	1	2		unhappy	neg	not happy	neg							exercise			
123	0	0	0	6		0	3	0	9	2	3	2		good	pos	pretty good	pos							exercise			
122	1	0	0	12		1	2	0	7	2	4	4		Depressed	neg	too heavy	neg										depression
121						1	3	1	12	3	4	3															
120	0	0	0	10		2	2	2	12	2	4	4		very unhappy	neg	very unhappy	neg							exercise			

CHECK	what methods worked themes and codes					what works	num	comment			are these the same							
	main method that worked	why worked	methods tried	what exercise now	what diet now	what WM works now if clear			monitoring	lifestyle ap	adapting	taking actic	portion control		support		motivation	num	
141	intake control, exercise					nothing				lifestyle		taking cont	portion control				self-image	1	WG2
140	nothing worked					nothing											keep mobile	1	AWM (HW
139	slimming world					nothing									family				
138	nothing worked					nothing long term													
137	nothing worked					underweight issue													
136	nothing worked																		
135	nothing worked					nothing													
134	nothing worked		medications			nothing													
133	self-chosen diet	lifestyle approach	NA+SCD+EC		skip lunch	healthy lifestyle									self		avoid surgery	1	WG3
132	nothing worked		NA+SCD+PA+EC+SDE			nothing													
131	self-chosen diet and exercise class		SCD+EC	pilates	F&V														
130	nothing worked		SCD			nothing													
129	nothing worked		SCD			nothing													
128	intake control		SCD		intake control	intake control		gradual introduction							self				
127	intake control		SCD			intake control													
126																			
125	weightwatchers		NA+SCD+EC+SDE	walk slowly					weighed weekly										
124	nothing worked		SDE	walk	intake control	nothing													
123	exercise		NA+SDE			self-directed exercise													
122	self-chosen diet		NA+SCD+PA+EC+SDE+M			nothing													
121																			
120	weightwatchers		SCD+PA+EC+SDE	exercise class		nothing													

	quote - beliefs, ie a cuase that is directly attributed to weight gain and nothing else can be done		WM type BV	BMI BK	method s score CH	polio score CM	mobilit y CN	walkabil ity CO	activity CP	method worked DB	because statement		
2	from q13 feelings												
3	not happy at all because of my inability to actually lose any weight	134	WG4	42	2	13	4	4	3	nothing worked	inability to lose		
4	not really happy, it is a bit harder to lose when one gets a bit older. That is why I walk as much as possible dont really diet, just cut down on foods etc	124	WG1	30	4	2	1	1	2	nothing worked	age		
5	I am very unhappy about being overweight. I was never overweight when I was a child but it is a family trait on my mother's side although my brother isn't overweight	91	AWM (OB2)	40	5	6	4	4	4	dietician	family trait		
6	I am trying to lose weight and keep weight off my legs I feel it is a losing battle as I cannot get enough exercise. I go swimming twice a week but it doesn't seem to help. If you can come up with something please let me know	78	AWM (OW)	28	4	8	2	3	3	nothing worked	not enough exercise		
7	I feel that I need to try to be as active as possible within the confines of my wheelchair, as when walking this was very hard work (like a good workout) to walk around. Now of course, i don't get this kind of exercise. However, I also feel my weight gain is part of the ageing process	67	WG1	25	4	9	3	4	4	gym (physio + trainer + individual plan)	age		
8	could do with losing 2-3 stone but can't exercise and am only eating 2000-2500 cals/day not much I can do about it	62	WG2	39	9	9	1	3	3	nothing worked	cant exercise	only eating 2000c	not much can do
9	Frustrated!! No matter how little I eat I do not seem to be able to loose any weight in fact as time goes by I just seem to put on more and more weight. I do realize that the problem is lack of mobility and I should eat less and less but hey..you only have one life, and it's short!	26	WG2	30	2	14	2	2	3	self-chosen diet	lack of mobility	inability to lose	
10	unable to exercise and enjoy food	24	WG2	33	0	10	4	4	3	0	cant exercise		
11	Frustrated - it is such a struggle to maintain a healthy weight especially as I cannot do a lot of physical exercise. I am embarrassed about the shape of my body due to my weight and wish that there was more support for disabled people to participate in specially constructed exercise plans which take the individuals physical capabilities into account.	15	WG1	29	3	15	4	4	3	nothing worked	cant exercise		
12	ago and have a stoma, well managed, but i seem to be one mass of scars and hacked up body -having had polio has always left me feeling clumsy, muscles bum and don't work, would be easy to give up and think of it every day, but have good family and friends and interests - distract myself and do not discuss my deeper feelings, for the moment, just get on with it - my latest efforts as i have a litle/big voice in my head all the time that says, must try harder, do more - everyone seems to think it's my/our fault if i/we don't exercise in a convential way - is to ask my gp for a gym referral, he laughed and wrote it for me on prescription, i await to hear there is considerable dissonance between my feelings and what i hear from people - i wear makeup, good interesting clothes and jewelry, some think i'm lovely, beautiful, funny, clever and have a spirited personal and political identity but losing weight is like a vertical mountain that i cannot conquer, it just doesn't shift i don't believe in diets, just good eating habits, enjoying food and company, occasional glass of wine, but as it gets more difficult and painful to move around, my frustration and depression increases as if i'm being smothered i fantasise that if i was lighter i would be a free spirit, so there's no telling that being thinner might confirm even worst fears! i don't hate myself, in fact i feel very, very sad for myself - i hate polio and the feeling that i am shackled to it ,and its embodied in my weight, which is the way it is because i can't run up mountains my husband adores me physically and in every other way - he thinks we should accept things as they are and not waste energy on rage well, i still rage	9	0	0	12	6	2	3	3	nothing worked	polio embodied in weight		
13	I feel very uncomfortable because it seems to affect my walking & without being able to walk very far I feel I am not getting enough excercise which is keeping my weight high.	8	WG1	29	4	3	2	2	3	self-chosen diet	not enough exercise		
14	from q16 difficulties												
15	not being able to exercise	136	WG2	34	5	11	2	3	3	No	cant exercise		
16	lack of ability to exercise	135	WG4	40	4	6	2	3	4	No	cant exercise		
17	because of my inability to do any effective exercise to lose any weight being mainly confined to an electric wheelchair	134	WG4	42	2	13	4	4	3	No	cant exercise		
18	Although this is the heaviest I have been I think a lot is because of my age & not being so mobile because of this I try to eat sensibly instead of yo-yo dieting	131	LWM	25	6	9	2	3	2	yes	age	lack of mobility	
19	lack of will power is the only explanation	130	0	0	2	9	3	4	3	No	will power		
20	never felt 'really overweight'	127	WG1	30	1	15	2	3	3	yes	not overweight		but is
21	I can not do excrice as it tires me out. So it is hard to loos weight.	105	WG1	26	5	9	2	4	4	No	cant exercise		
22	not being able to exercise properly without pain	101	WG2	34	17	6	1	4	1	yes	cant exercise		
23	Weight slowly increased with age, which is something my able bodied friends have also experienced, the difference is I find it difficult to improve my level of aerobic fitness without causing pain.	98	0	25	8	6	2	4	3	yes	age		
24	lack of exercise due to my condition and eating too much of the wrong foods	92	WG2	32	4	9	2	3	4	No	cant exercise	wrong foods	
25	Lack of mobility. No use in legs. If I use arms/shoulders to exercise I will wear them out.	81	WG1	27	2	13	3	4	3	yes	lack of mobility	will wear arms out	

Appendix 9. Polio background; additional data

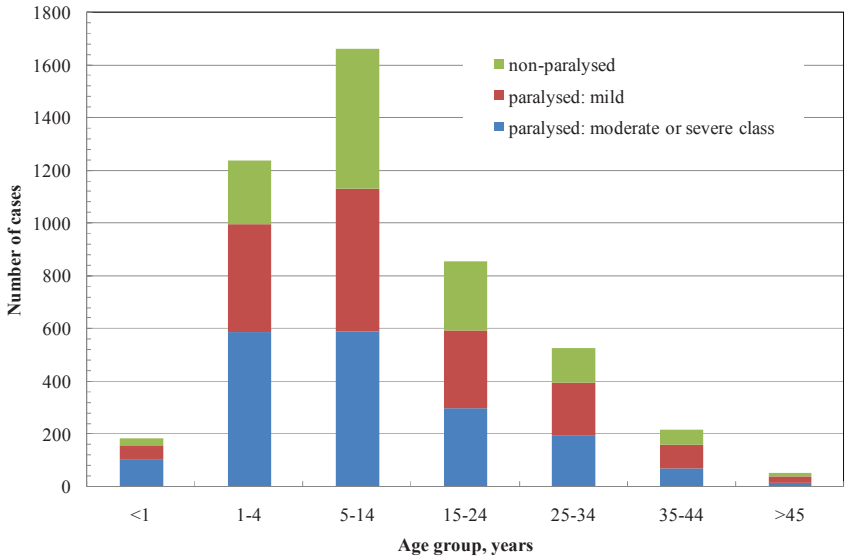
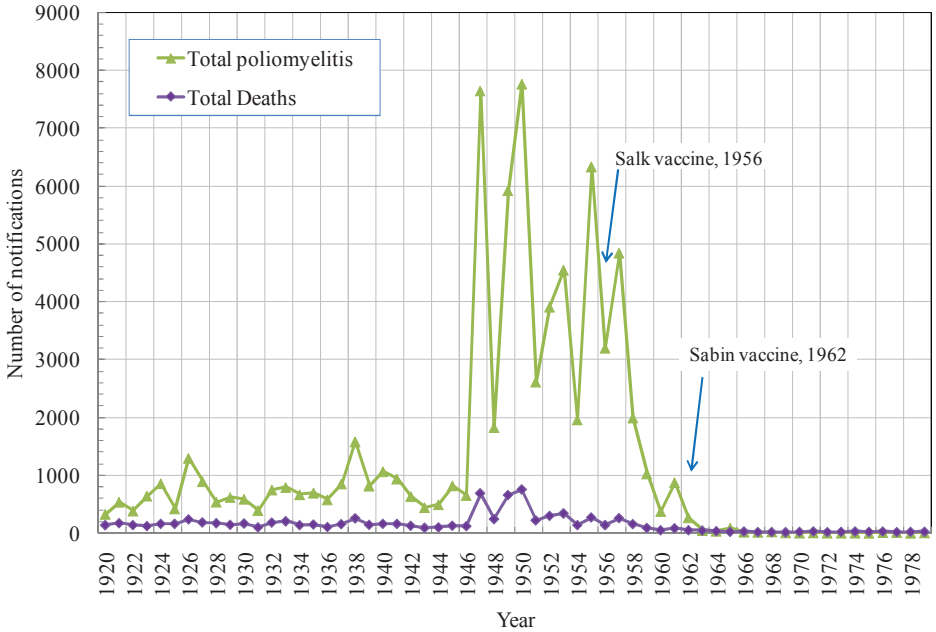


Figure 1. Severity of polio by age of contraction (Bradley & Gale, 1948)

9.1.1 Number of cases per year

The number of cases reported peaked in the mid twentieth century with a rapid decrease following the development of effective vaccines (Salisbury, Ramsay, & Noakes, 2006). The disease is not yet eradicated worldwide, with 1 352 cases worldwide in 2010 and a trickle of cases in the UK even a recently in the 1990's



Appendix 10. Example output from PASW Statistics 18

10.1 Differences between two groups

Mann-witney U testing for difference in BMI between 'cant exercise' group and 'dont say' group

Test Statisticsa

	BMI
Mann-Whitney U	896.000
Wilcoxon W	2787.000
Z	-3.190
Asymp. Sig. (2-tailed)	.001

p<0.05 so significant difference

median and range as not ND

Descriptives

cant exercise or dont say			Statistic	Std. Error
BMI	cant exercise	Mean	32.049	1.00007
		95% Confidence Interval for Mean Lower Bound	30.0350	
		95% Confidence Interval for Mean Upper Bound	34.0635	
		5% Trimmed Mean	31.4732	
		Median	30.6693	
		Variance	46.006	
		Std. Deviation	6.783	
		Minimum	20.89	
		Maximum	55.18	
		Range	34.29	
		Interquartile Range	7.50	
		Skewness	1.437	.350
		Kurtosis	2.758	.688
	dont say	Mean	28.234	.93554
		95% Confidence Interval for Mean Lower Bound	26.3626	
		95% Confidence Interval for Mean Upper Bound	30.1053	
		5% Trimmed Mean	27.6745	
		Median	25.7507	
		Variance	53.389	
		Std. Deviation	7.307	
		Minimum	18.12	
		Maximum	50.40	
		Range	32.29	
		Interquartile Range	7.07	
		Skewness	1.173	.306
		Kurtosis	1.221	.604

Tests of Normality

cant exercise or dont say		Kolmogorov-Smirnova		
		Statistic	df	Sig.
BMI	cant exercise	.126	46	.065
	dont say	.162	61	.000

Shapiro wilk as N<100
sig<0.05 so not normally distribute
use Mann Witney U

Test of Homogeneity of Variance

		Levene Statistic	df1	df2	Sig.
BMI	Based on Mean	.638	1	105	.426
	Based on Median	.316	1	105	.575
	Based on Median and with adjusted df	.316	1	103.768	.575
	Based on trimmed mean	.524	1	105	.471

meets assumption of homogeneity of variance

Ranks

cant exercise or dont say		N	Mean Rank	Sum of Ranks
BMI	cant exercise	46	65.02	2991.00
	dont say	61	45.69	2787.00
	Total	107		

10.2 Correlations between disability and mobility parameters

Tests of Normality

	Kolmogorov-Smirnova			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
bmi	.136	107	.000	.930	107	.000
polio	.087	107	.047	.982	107	.161
mobility	.313	107	.000	.808	107	.000
walkability	.231	107	.000	.848	107	.000
activity	.245	107	.000	.808	107	.000
methods	.137	107	.000	.933	107	.000

Correlations

			bmi	polio	mobility	walkability	activity	methods
Spearman's rho	bmi	Correlation Coefficient	1.000	.007	.103	.249	.238	.245
		Sig. (2-tailed)	.	.943	.292	.010	.013	.011
		N	107	107	107	107	107	107
	polio	Correlation Coefficient	.007	1.000	.342	.291	.190	-.144
		Sig. (2-tailed)	.943	.	.000	.000	.024	.089
		N	107	141	141	141	141	141
	mobility	Correlation Coefficient	.103	.342	1.000	.671	.343	-.121
		Sig. (2-tailed)	.292	.000	.	.000	.000	.151
		N	107	141	141	141	141	141
	walkability	Correlation Coefficient	.249	.291	.671	1.000	.420	-.053
		Sig. (2-tailed)	.010	.000	.000	.	.000	.530
		N	107	141	141	141	141	141
	activity	Correlation Coefficient	.238	.190	.343	.420	1.000	.221
		Sig. (2-tailed)	.013	.024	.000	.000	.	.009
		N	107	141	141	141	141	141
	methods	Correlation Coefficient	.245	-.144	-.121	-.053	.221	1.000
		Sig. (2-tailed)	.011	.089	.151	.530	.009	.
		N	107	141	141	141	141	141

Appendix 11. Table of UK Qualitative Studies on Long term Experiences with Weight Management

study	subjects	Key general findings of relevance	reference
Qualitative interviews to study experiences with weight control over lifespan Thematic analysis	N=20, 15 female, 5 male 35-64 yrs old, Scotland Recruited by invitation or posters at a university	Defined lifetime weight maintainers, active weight maintainers and weight gainers Identified a staged approach used by successful weight maintainers - monitoring, defined weight goal or band, defined trigger point for taking action, acting quickly with range of coping strategies Weight gainers had emotional reaction to weight, poorly defined goals, taking action was mood dependant, disliked or didn't use exercise, weight loss was separate from usual life Focuses on how weight loss intervention is built into daily life, not on detail of weight loss method.	(Chambers & Swanson, 2012)
Qualitative interviews to study female slimmers perspectives of weight gain causes Thematic analysis	N=11, all female 28-72 yrs old Recruited from East Midlands slimming clubs	Main beliefs were that behaviours caused weight gain including habits, life triggers where food provided comfort, childhood experience of food and attached meanings, use of food to deal with internal emotions (emotions expressed as hunger) Motivated by research on how weight loss is affected by the subjects belief on what caused the weight gain, for example, belief in a physical or medical cause resulted in poorer weight management (relevant to polio?) - possible use in developing treatments	(Sawkill, Sparkes, & Brown, 2012)
Qualitative interviews to study male slimmers perspectives on dieting Discourse analysis and grounded theory	N=8, all male 33-57 yrs old 6 recruited via London slimming clubs	Two categories emerged from the study: legitimacy in that subjects viewed that men dieted for more legitimate motives such as medical reasons compared to women, and supported using sensible diets based on healthy eating rather than 'crash diets'. Also support, most subjects referred to emotional support from their partners and friends though with some reference to responsibility for dieting 'handed over to their partners' The paper also discussed research on male body image with pressure to look bigger, more muscular	(de Souza & Ciclitira, 2005)
Qualitative interviews to study perceptions of people who have maintained > 10% weight loss for >1yr Thematic analysis	N=10, all female due to lack of male volunteers 44 +/- 12 yrs Recruited via adverts but mostly directly by researchers	Most subjects were motivated by health reasons (cf mens view), had tried many approaches and lost weight but regained. Key realization was need for a permanent lifestyle change involving not banning foods, living by a set of rules or boundaries, listening to their bodies, monitoring, accepting lapses but reacting quickly to refocus. Same as chambers list An issue in the maintenance phase was the lack of 'positive reinforcement' from visible weight loss and positive comments from others even though significant effort was required. This was compensated by new roles or goals such as role modeling for others or exercise goals (cf new identity). Autonomous motivation and increased activity were cited as important	(Hindle & Carpenter, 2011)
Qualitative interviews to study identity shift following weight loss Thematic analysis	N=10 female 26-58yrs, recruited via survey of a slimming organisation	The study resulted in two themes: a restricted self before weight loss with a weight centered identity with food as an emotional regulation tool (fat=ugly=negative mood) and a 'liberated' self with positive self-image, flexible dietary habits and a broader self-identity. Success required a change from short term diet to long-term lifestyle change. The transition was 'reinforced by benefits of weight loss' cf polio still being deformed comment	(Epiphaniou & Ogden, 2010)